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QUALIDADE DE VIDA, PERCEPÇÃO DE SAÚDE, RESILIÊNCIA, AUTO-REGULAÇÃO E SUPORTE SOCIAL NOS ADOLESCENTES PORTUGUESES COM DOENÇA CRÓNICA

[QUALITY OF LIFE, PERCEPTION OF HEALTH, RESILIENCE, SELF-REGULATION AND SOCIAL SUPPORT IN PORTUGUESE ADOLESCENTS WITH CHRONIC DISEASE]

Teresa Cristina da Cruz Fatela dos Santos

Tese submetida como requisito parcial para obtenção do grau de
[Thesis submitted as partial requisite for the Degree of]

Doutoramento em Psicologia
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Área de especialidade..... (Psicologia da Saúde)
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Tese apresentada para cumprimento dos requisitos necessários à obtenção do grau de Doutor em Psicologia na área de especialização Psicologia da Saúde, realizada sob a orientação da Professora Margarida Gaspar de Matos e co-orientação da Professora Maria Celeste Simões e Professora Maria do Céu Machado, apresentada no ISPA - Instituto Universitário no ano de 2016.

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To my parents and my grandmother,

To all my beloved ones, who have been always standing by my side…

"What makes a good quality of life?"

(Payot & Barrington, 2011)

"Optimism should be the only chronic disease of young people caregivers…"

(George Steiner, cit. por Machado, M.C. in ACS, 2009)

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This cycle is for now closed, but hopefully, just to start a new one, with fresh challenges and synergies… because "*every new beginning comes from other beginning's end"* (*Seneca*).

Teresa Santos

Palavras-chave:

Adolescentes; Doença crónica; Qualidade de Vida (Relacionada com a Saúde); Factores Psicossociais

Key words:

Adolescents; Chronic Disease; (Health-related) Quality of life; Psychosocial Factors

Categorias de Classificação da Dissertação [Classification Categories of the thesis]*:

3300 Health & Mental Health Treatment & Prevention

3360 Health Psychology & Medicine

3361 Behavioural & Psychological Treatment of Physical Illness

3365 Promotion & Maintenance of Health & Wellness

*PsycINFO Classification Categories and Codes – please note that this classification code system was designed to describe the content of the PsycINFO database, not the field of psychology.

ABSTRACT

The impact of chronic disease on Quality of Life(QoL)/Health-related Quality of Life(HRQoL) and psychosocial functioning in adolescence is a complex phenomenon. This research work aimed to: 1) characterize QoL/HRQoL and psychosocial functioning in chronically ill adolescents at a national-representative level; 2) explore associations between chronic disease, QoL/HRQoL and psychosocial factors; and 3) characterize QoL/HRQoL and psychosocial functioning in chronically ill adolescents in a clinical context.

This work comprised three phases. Phase I used cross-sectional data from the national study Health Behaviour in School-aged Children (2010), conducted in 5050 adolescents (52.3% girls, 14±1.85 years old). Comparisons between adolescents having/not having chronic disease were performed; afterwards within the chronically ill subgroup, adolescents feeling affected/not affected in school participation were compared. Individual-psychological variables (wellness perception, life satisfaction, psychological well-being) and also socio-contextual variables (satisfaction with family environment, perceived school performance, pressure with schoolwork and risk behaviours) were assessed. Phase II was a systematic review on the association between chronic disease, HRQoL and psychosocial factors. Phase III used cross-sectional data collected in a clinical context in 135 adolescents (51.9% boys, 14±1.5 years old), with diabetes *mellitus*, allergic, or neurological diseases. Comparisons by type of chronic diseases were conducted, and then, between adolescents feeling affected/not affected in their school/social participation. HRQoL, psychosomatic health, resilience, self-regulation and social support were measured in this Phase.

The main findings (set of nine scientific articles) suggested that: 1) at a national-representative level, adolescents with chronic diseases reported high risk on individual-psychological and socio-contextual outcomes, *vs.* healthy peers. The most vulnerable chronically ill adolescents were the older, girls, those with lower socioeconomic status and feeling affected in their school participation; 2) literature showed an association between having chronic disease in adolescence and negative HRQoL outcomes and psychosocial functioning, as well as lack of specific studies on adolescence as an independent age group; 3) in the clinical context, girls and adolescents who felt affected in their school/social participation, reported worse HRQoL outcomes and psychosocial functioning; no differences were observed by type of diseases. Considering the whole group, adolescents who felt affected in participation in school/social activities reported worse HRQoL, psychosomatic health, resilience, self-regulation and social support; girls had worse HRQoL and psychosomatic health, *vs.* boys. Psychosomatic health, resilience and self-regulation had a higher impact in some HRQoL's dimensions for boys, whereas social support for girls. Overall, psychosomatic health, resilience, self-regulation and social support were positively associated with HRQoL, even when combined with clinical variables.

These findings in Portuguese adolescents enhance the understanding of the impact of chronic disease on QoL/HRQoL and psychosocial functioning, underlining the role of protective factors on positive outcomes. It stressed as a current challenge for research and clinical practice, to include a routine assessment of these variables in adolescents, also suggesting a multidimensional and individualized approach, including self-reports to "give voice" to young people's needs. Identifying impaired domains optimizes allocation of available resources and

helps healthcare professionals to implement multidisciplinary and cost-effective interventions for psychosocial support. Ultimately, a wider framework with clinicians, schools, family, and peers is strongly suggested, particularly relevant for the Portuguese reality, since this assessment is not common and psychosocial interventions are still scarce.

RESUMO

O impacto de doenças crónicas na Qualidade de Vida(QV)/Qualidade de Vida Relacionada com a Saúde(QVRS) e no funcionamento psicossocial é um fenómeno complexo. Este trabalho procurou: 1) caracterizar a QV/QVRS e funcionamento psicossocial em adolescentes com doenças crónicas ao nível representativo nacional; 2) explorar as associações entre o impacto da doença crónica na adolescência, QV/QVRS e funcionamento psicossocial; e, 3) caracterizar a QV/QVRS e funcionamento psicossocial em adolescentes com doenças crónicas em contexto clínico.

O presente trabalho integrou três fases. A Fase I usou dados transversais do estudo nacional *Health Behaviour in School-aged Children* (2010) em 5050 adolescentes (52.3% raparigas, 14±1.85 anos de idade). Foram feitas comparações entre adolescentes com/sem doença crónica, e, dentro do grupo dos que tinham doença crónica, foram comparados os adolescentes que se sentiam afectados/não afectados na participação escolar. Variáveis individuais-psicológicas (percepção de saúde, satisfação com a vida e bem-estar psicológico) e socio-contextuais (satisfação com a família, auto-percepção de competência escolar, pressão com os trabalhos escolares e comportamentos de risco) foram avaliadas. A Fase II consistiu numa revisão sistemática sobre associações entre doenças crónicas, QVRS e factores psicossociais. A Fase III usou dados transversais recolhidos em contexto clínico em 135 adolescentes (51.9% rapazes, 14±1.5 anos de idade), com diabetes *mellitus*, doenças alérgicas ou neurológicas. Foram feitas comparações estratificando para o tipo de doença, e entre adolescentes que se sentiam afectados/não afectados na participação escolar/social. A QVRS, saúde psicossomática, resiliência, auto-regulação e suporte social foram avaliados nesta fase.

Os resultados (nove artigos científicos) sugeriram: 1) ao nível representativo nacional, os adolescentes com doenças crónicas apresentaram maiores riscos nas variáveis individuais-psicológicas e socio-contextuais, *vs.* adolescentes saudáveis. Os adolescentes com doenças crónicas mais vulneráveis eram mais velhos, raparigas, com estatuto socioeconómico mais baixo e os que se sentiam afectados na participação escolar; 2) a literatura demonstrou uma associação entre doenças crónicas na adolescência e resultados negativos na QVRS e funcionamento psicossocial, bem como escassez de estudos na adolescência como grupo etário independente; 3) no contexto clínico, as raparigas e adolescentes afectados na participação escolar/social apresentaram piores resultados na QVRS e funcionamento psicossocial; não se verificaram diferenças de acordo com o tipo de doença. Na totalidade do grupo, os adolescentes afectados na sua participação escolar/social reportaram resultados mais baixos na QVRS, saúde psicossomática, resiliência, auto-regulação e suporte social, especialmente QVRS e saúde psicossomática nas raparigas, *vs*. rapazes. Contudo, particularmente em algumas dimensões da QVRS, as variáveis saúde psicossomática, resiliência e auto-regulação tiveram mais impacto nos rapazes, e o suporte social nas raparigas. Saúde psicossomática, resiliência, auto-regulação e suporte social tiveram associação positiva com QVRS, mesmo quando combinadas com variáveis clínicas.

Estes resultados em adolescentes Portugueses aumentam a compreensão do impacto da doença crónica na QV/QVRS e funcionamento psicossocial, realçando o papel relevante de factores protectores para resultados positivos. Evidenciaram ainda o desafio actual para a investigação e prática clínica que é a inclusão da avaliação regular destas variáveis em adolescentes, sugerindo uma abordagem multidimensional individualizada incluindo questionários de

autopreenchimento, permitindo dar “mais voz” aos jovens e às suas necessidades. Identificar áreas de maior vulnerabilidade permitirá a optimização de recursos existentes e poderá auxiliar os profissionais de saúde na implementação de intervenções de apoio psicossocial multidisciplinares eficazes. É assim fortemente sugerida uma perspectiva abrangente com clínicos, escolas, famílias e pares, particularmente relevante para a realidade Portuguesa, dado que esta avaliação é pouco utilizada e as intervenções psicossociais são ainda escassas.

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LIST OF ABBREVIATIONS AND ACRONYMS

ACS: Alto Comissariado para a Saúde

AFPSCH: Affects school participation.

AFPLTF: Affects participation in leisure time with friends.

APA: American Psychological Association

AUT: Autonomy

BUL: Being Bullied

CDC: Centers for Disease Control and Prevention

CHLN EPE: Centro Hospitalar Lisboa Norte

DGS: Direcção-Geral da Saúde

EMO: Mood and Emotions

EPE: Entidade Pública Empresarial

FAS: Family Affluence Scale

FIN: Financial Resources

GINA: Global Initiative for Asthma

HRQoL: Health-related Quality of Life

HBSC: Health Behaviour in School-aged Children

ICD: International Classification of Diseases

INE: Instituto Nacional de Estatística

QoL: Quality of Life

NASS: Need for Activities connected to Social Support

NCD: Non communicable diseases

OPP: Order of Portuguese Psychologists

OPSS: Observatório Português dos Sistemas de Saúde

PAR: Parent Relation & Home Life

PBW: Psychological Well-being

PHY: Physical Well-being

PLTF: Participation in leisure time with friends

PSCH: Participation in school

RES: Resilience

SCL: Symptoms Check List-HBSC-SCL (Psychosomatic Complaints)

SEL: Self-perception

SES: Social Economic Status

SCH: School Environment

SOC: Social Support and Peers

SR: Self-regulation

SR-LT : Self-regulation, Long Term

SR-ST: Self-regulation, Short Term

SSS: Satisfaction with Social Support

SSSS: Scale of Satisfaction with Social Support

UNICEF: United Nations Children's Fund

WHO: World Health Organization

WMA: World Medical Association

WHOQOL: The World Health Organization Quality of Life

STRUCTURE OF THE DISSERTATION

This PhD thesis is the result of a research study conducted as part of the Doctoral Programme in Psychology, speciality of Health Psychology at *ISPA, Instituto Académico* (Academic Institute) in Lisbon, Portugal. It was carried out in *Aventura Social* research group of the *Faculdade de Motricidade Humana, FMH/Universidade de Lisboa, UL* (Faculty of Human Kinetics/University of Lisbon) and the former *Centro de Malária e Doenças Tropicais, CMDT/Universidade Nova de Lisboa* (Centre for Malaria and other Tropical Diseases/Nova University of Lisbon) (CMDT I&D unit of the Portuguese Foundation for Science and Technology, Portugal). Additionally, it was also conducted in *Consulta Externa de Pediatria do Departamento de Pediatria do Hospital de Santa Maria* (Outpatient Paediatric Department of the Paediatric Department of Santa Maria Hospital), integrated in *Centro Hospitalar de Lisboa Norte* – CHLN EPE (North Lisbon Hospital Centre).

The research was entirely supervised by Professor Dr. Margarida Gaspar de Matos, Professor of International Health at FMH/UL; *ISAMB, Instituto Saúde Ambiental, Faculdade de Medicina/Universidade de Lisboa* (Environmental Health Institute, Medicine Faculty/University of Lisbon); William James Center for Research, *ISPA- Instituto Universitário*; Director of *Aventura Social* research group and Principal investigator of the Portuguese Health Behaviour in School-aged Children - HBSC Portugal. The research was also co-supervised by Professor Dr. Maria Celeste Simões (FMH/UL; *ISAMB, Instituto Saúde Ambiental, Faculdade de Medicina/Universidade de Lisboa*), and Professor Dr. Maria do Céu Machado (*Faculdade de Medicina*/UL; *Departamento de Pediatria do Hospital de Santa Maria; CAML, Centro Académico de Medicina de Lisboa/*Medicine Academic Centre of Lisbon). In addition, the period of this research work also included a supplementary research and scientific discussion activities at: 1) *Institut National de la Santé et de la Recherche Medicale (INSERM) - Université Paul Sabatier (Équipe 2 de l'UMR 1027)*, under the supervision of Professor Dr. Emmanuelle Godeau (Toulouse, France); and 2) Departament of *Psicología Evolutiva y de la Educación de la Universidad de Sevilla* (Sevilla, Spain), with the supervision of Professor Dr. Mª Carmén Moreno (which resulted additional publications that are not in the aim of the discussion in the present thesis, but were included in Part IV–Annexes, Chapter XVI).

The body of the present dissertation will be organized in four parts, herein described.

Part I | Introduction - Theoretical Framework offers an overview of the current state of the art concerning the impact of living with a chronic disease in the crucial period of adolescence. **Chapter I** focus on a general overview of chronic disease in adolescence, starting with a brief definition and evolution of the concept of chronic disease, its assessment, and evaluation, as well as epidemiological data. This chapter ends with the specific relationships of chronic disease and adolescence. **Chapter II** discusses Quality of Life (QoL), Health-related Quality of Life (HRQoL) and psychosocial development in the context of chronic disease. This chapter starts by describing the relevance of psychosocial factors and clarify some related issues of QoL and HRQol. In addition, it addresses the impact of living with chronic disease in HRQoL and in psychosocial development and ends by pointing out some challenges for health related behaviours (protection and risk factors). **Chapter III** presents relevant conceptual models related with chronic diseases and with the present research. **Chapter IV** offers the concluding remarks that guided the theoretical formulation of general and specific research goals for the present thesis. Subsequently, **Chapter V** describes the research general and specific objectives as well as the conceptual/methodological aspects, taking into account the three phases comprised in the present research work.

Part II | Systematic Review and Empirical Studies is composed by nine original studies, in the format of scientific articles, that have been published, are submitted or in press, in international peer-reviewed journals. An individualized and detailed description of the objectives and methodology for each article is described within the respective sections. Chapters in this Part II were organized according to the articles, within the different phases. **Chapter VI** includes the empirical studies 1, 2, 3 and 4 (**Research Phase I**), that explored and characterized the psychosocial functioning of adolescents with chronic diseases, through the analysis of the HBSC/WHO Portuguese Survey conducted in 2010, in a national-representative sample. **Chapter VII** shows the scientific article 5 (**Research Phase II**), that clarified the associations between living with a chronic disease and the impact on QoL/HRQoL and psychosocial factors, particularly in the specific age group of adolescence. Finally, **Chapter VIII** presents the empirical studies 6, 7, 8 and 9 (**Research Phase III**), that explored and characterized the impact of chronic disease on HRQoL and psychosocial factors, including protective ones reported in the literature, specifically in a clinical population of Portuguese adolescents, in an outpatient department in a hospital context.

Part III | Discussion and Conclusion provides a summary and an integrated discussion of the main findings of the present research. General and specific proposed goals were revisited, within a conceptually integrated framework (**Chapter IX**), and in **Chapter X** the limitations and strengths of the study were critically appraised. The theoretical implications and potential future directions for research, clinical practice in paediatric settings and health/education policies, specifically in the crucial period of adolescence are discussed in **Chapter XI**. General conclusions are presented in **Chapter XII** and bibliographic references in **Chapter XIII**.

Part IV | Annexes offers the most relevant attachments to this research dissertation, such as the Assessment Protocols of Phases I and III, including the respective ethical approvals, informed consents and instruments (**Chapters XIV** and **XV**). This Part IV also contains a list of supplemental publications related to the theme of the present thesis (**Chapter XVI**).

LIST OF ARTICLES THAT FORM THE SCIENTIFIC AND EMPIRICAL BASIS OF THIS DISSERTATION

Empirical Study 1: Santos, T., Matos, M. G., Simões, C., Fonseca, H., & Machado, M. C. (2013). Individual factors related to chronic condition in Portuguese adolescents: Highlights from the HBSC/WHO study. *Health, Special Issue on Chronic Diseases Research, 5*(11B), 25-34. doi: 10.4236/health.2013.511A2005

Empirical Study 2: Santos, T., Matos, M. G., Simões, C., & Machado, M. C. (2015). Psychological well-being and chronic condition in Portuguese adolescents. *International Journal of Adolescence and Youth, 20*(3), 334-345. doi: 10.1080/02673843.2015.1007880

Empirical Study 3: Santos, T., Matos, M. G., Simões, C., & Machado, M. C. (2016). Contextual factors related to chronic condition in Portuguese adolescents: Highlights from the HBSC/WHO study [Factores Contextuais em Adolescentes Portuguese com Doença Crónica: Highlights do Estudo HBSC/OMS]. *Psicologia: Reflexão e Crítica, 29*(3). doi: 10.1186/s41155-016-0008-x

Empirical Study 4: Santos, T., Ferreira, M., Simões, M.C., Matos, M. G., & Machado, M.C. (2014). Chronic Condition and Risk Behaviours in Portuguese Adolescents.*Global Journal of Health Science, 6*(2), 227-36. doi: 10.5539/gjhs.v6n2p227

Scientific Study 5, Systematic Review: Santos, T., Matos, M.G., Simões, C., & Machado, M.C. (2015). (Health-related) quality of life and psychosocial factors in adolescentes with chronic disease: a systematic literature review. *BMC Health and Quality of Life Outcomes*. (Manuscript submitted for publication).

Empirical Study 6: Santos, T., Matos, M.G., Marques, A., Simões, C., Leal, I., & Machado, M.C. (2016). Psychosocial Profile In Portuguese Adolescents With Chronic Disease Attending An Outpatient Department In A Hospital Setting. *European Journal of Pediatrics.* (Manuscript submitted for publication).

Empirical Study 7: Santos, T., Matos, M.G., Marques, A., Simões, C., Leal, I., & Machado, M.C. (2015). The Impact of Chronic Health Conditions and Related Psychosocial Factors in Adolescence. *BMC Pediatrics.* (Manuscript submitted for publication).

Empirical Study 8: Santos, T., Matos, M.G., Marques, A., Simões, C., Gaspar, T., Leal, I., & Machado, M.C. (2016). Gender Differences In Health-Related Quality Of Life Of

Adolescents With A Chronic Disease In A Clinical Context. *Child & Youth Care Forum.* (Manuscript submitted for publication).

Empirical Study 9: Santos, T., Matos, M.G., Marques, A., Simões, C., Leal, I., & Machado, M.C. (2016). Do Clinical And Psychosocial Factors Affect Health-Related Quality Of Life In Adolescents With Chronic Diseases? *Quality of Life Research.* (Manuscript submitted for publication).

A list of supplemental publications related to the theme of the present thesis is also presented below and more information is included in Part IV–Annexes, Chapter XVI.

Abstract:

- Santos, T., Matos, M.G., Gaspar, T., Simões, C., Leal, I., & Machado, M.C. (2015). Health-related quality of life in adolescents with chronic conditions: highlights from the Portuguese HBSC – 2014. *EIP – Excellence in Pediatrics, 7th Edition, Conference Programme (London, UK), ID:182 / OP1-RD-CC:Presentation 2*, 66. http://www.ineip.org/content/abstract/1524/op-182-2015-health-related-quality

Papers:

- Pacoricona, D., Santos, T., Matos, M.G., Ehlinger, V., Stanislas, S., Sentenac, M., & Godeau, E. (2016). Expérimentation du cannabis chez des élèves d'ULIS avec déficience cognitive. *Courrier des Addictions* (*submitted*).
- Santos, T., Matos, M.G., Simões, C., & Machado, M.C. (2014, *accepted*). Adolescentes com Doença Crónica em Setting Hospitalar: Perspectivas Qualitativas [Adolescents with Chronic Diseases in a Hospital Seeting: Qualitative Perspectives]. *Actas do 2º Congresso da Ordem dos Psicólogos Portugueses e IX Congresso Ibero-Americano de Psicologia*. Portugal: Lisboa.
- Santos, T., Matos, M.G., Simões, C. Camacho, I., Tomé, G., & Moreno, M.C. (2013). Estilos Parentais E Desenvolvimento Positivo Em Crianças e Adolescentes Com Doença Crónica. [Parenting styles and positive development in children and adolescents with chronic condition]. *Revista de Psicologia da Criança e do Adolescente, Journal of Child and Adolescent Psychology, 4*(2), 185-204. http://revistas.lis.ulusiada.pt/index.php/rpca/article/view/429/409

Chapter of Books:

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PART I - INTRODUCTION, THEORETICAL FRAMEWORK

Chapter I

General Overview of Chronic Disease in Adolescence

1. Chronic Disease: Definition and Concept

Infant mortality rates of several fatal chronic diseases have decreased over the past 40 years and the ability to manage successfully childhood-onset chronic diseases is one of the greatest advances in paediatric medicine (Maslow & Chung, 2013). Improvements in life expectancy and in survival rates, better functional outcomes and less hospitalizations were observed in several health conditions (Okumura, 2009). Therefore, changes occurred in rates of rarer conditions and large numbers of children with congenital or chronic conditions survive for a longer period of time into adolescence and adulthood, though with the consequences of the disease. Consequently, the prevalence of certain chronic diseases (such as diabetes, asthma or cancer survival) has increased and mortality has often been replaced by lifelong morbidity, with a risk for a healthier emotional and behavioural development (Compas, Jaser, Dunn, & Rodriguez, 2012; Delaney & Smith, 2012; Denny et al., 2014; Sattoe et al., 2015).

It is estimated that around 10% of adolescents suffer from a chronic disease affecting daily life, and there is a trend for further increase (Delaney & Smith, 2012), turning it into a challenge for health care systems and an increasing global public health concern (Lansdown, 2011; Suris, Michaud & Viner, 2004; Michaud, Suris, & Viner, 2007; UNICEF, 1989; WHOa; WHOb). This tendency can be considered as the *small epidemiologic transition*, and it is an extension of the *large epidemiologic transition* from acute to chronic diseases that took place in the middle of the last century (van der Veen, 2003).

The increase of survival rates bring considerable social consequences for health and psychosocial care planning, and in order to obtain valid and reliable prevalence of chronic diseases and health conditions, a clear definition was needed. Studies reported a wide variability in prevalence rates due to substantial diversity in concepts and operationalization in terms of source of information, method of information retrieval and study population (van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). In the literature several definitions could be found, some comprising only a measure of duration (Newacheck & Stoddard, 1994; Knottnerus, Metsemakers, Höppener, & Limonard, 1992), while many others based the

definitions on a combination of criteria, namely the duration of symptoms, the need for special health care or other requests, and the limitation in the daily activities (Feudtner, Christakis, & Connell, 2000; McPherson et al., 1998; Perrin et al., 1993; Stein, Bauman, Westbrook, Coupey, Ireys, 1993). These definitions are based on a generic or non-categorical approach, considering that the experience of living with chronic disease has common similarities in psychosocial consequences, independently of the disease itself (Pless & Perrin, 1985). Stein and colleagues (Stein et al., 1993) defined chronic health conditions as disorders that include: 1) biological, psychological, or cognitive basis; 2) lasted or are expected to last for at least 1 year; and 3) have one or more consequences on: a) limitations (functional and on physical, cognitive, emotional, and social growth and development); and, b) dependency (implying the need of medical specific treatments and interventions, or psychological and educational support over/above the usual for the child's age, or, in addition, special changes in accommodations at home/school contexts). Another non-categorical approach defines special health-care, when young people have or are at increased risk for a physical, developmental and emotional condition, and also need health and health-related services beyond what is generally required (McPherson et al., 1998).

In spite of a great variability in this field, robust and reproducible data were needed to compare prevalence over time and across countries. Thus, efforts have been done concerning the definition, measurement, categorization and prevalence of chronic diseases, in order to achieve international consensus concerning its conceptual definition in childhood (age range of 0-18 years old) (Mokkink, van der Lee, Grootenhuis, Offringa, & Heymans, 2008; van der Lee et al., 2007; Varni, Limbers, & Burwinkle, 2007).

Considering the work conducted in The Netherlands (Mokkink et al., 2008) and using the WHO (World Health Organizations) ICD-10 Classification (WHO, 1992), a disease or condition can be considered to be a chronic condition in childhood if: a) the diagnosis is based on medical scientific knowledge and can be established by professionals using reproducible and valid methods/instruments; b) it is not (yet) curable or, in case of mental health conditions, it is highly resistant to treatment; and, c) if present for longer than three months, it will probably last longer than three months, or, if it had occurred three times or more during the past year and will possibly recur again. More recently, the World Health Organization-WHO implemented the term "non-communicable diseases" (NCD), to define those that are not transmittable from person to person, that have a long-lasting duration, generally with a slow progression, referring to any extended/irreversible illnesses that usually can be controlled but not cured. The main

NCDs are cardiovascular diseases (e.g. myocardium infarction and stroke), cancers, chronic respiratory diseases (such as chronic obstructed pulmonary disease and asthma), diabetes (WHO, 2014b), obesity and arthritis (CDC, 2009).

It seems that the concept of a chronic condition implies the idea of permanence; however, it must be taken into account that conditions can change over time due to new treatments, characteristics of the disease itself, environmental factors and the child/adolescent's developmental phase (Van Cleave, Gortmaker, & Perrin, 2010). Despite the definition issues described above, the increased prevalence of chronic conditions in childhood brings substantial consequences not only for the entire society and health care systems, but also for the individual itself and his/her families. Young people living with a chronic disease will need long-lasting treatments, clinical attendance, proper support, and will manage daily symptoms and cope with complications and impairments. All of these adaptations can affect QoL and lead to the experience of acute consequences and health problems may reduce life expectancy. Thus, the label chronically ill *per se* does not give much information concerning medical, psychological and social consequences of the impact of living with chronic conditions, since it widely varies on young people's activity levels (Newacheck, McManus & Fox, 1991). In addition, great variability exists within each diagnostic category, foreseeing that diagnosis is not a very helpful categorization when investigating the disease's consequences (Stein & Jessop, 1989). On the other hand, health status, functional limitations and emotional responses to the disease, can better help to understand such consequences, since they are important determinants of well-being.

Facing this it may be considered that an objective and consensual definition of chronic condition was needed to examine prevalence; but to study the consequences of the disease, previous definitions found in the literature are extremely relevant (Feudtner et al., 2000; McPherson et al., 1998; Perrin et al., 1993; Stein et al., 1993). This concerns those consequences highlighting the functional limitations or health care needs, even if it is necessary to take into account variations according to cultural, educational and financial circumstances, as well as the availability of treatment and care (Mokkink et al., 2008). This is reinforced by literature pointing out that in national population studies in Western countries, there are 20-30% of teenagers with a chronic illness, and 10-13% of them reported that the disease substantially limited their daily life or needs, along with extended periods of care and supervision (Yeo &

Sawyer, 2005). Therefore and assuming that survival is no longer a challenge, a shift towards an optimal living with a chronic condition is necessary. It is suggested that, most likely, research and clinical practice need to address not only biological aspects of the disease, but also the psychosocial functioning that can mediate and promote a higher QoL/HRQoL and general well-being, including psychosocial variables and its link to adaptation processes and outcomes.

In the specific field of psychology, the definition of chronic disease is a flexible concept and has no strait limits, due to constant challenges and advances in medicine, that improve diagnosis, treatments and QoL (Davies, 1993). This definition considers that chronic disease and physical disability are existential experiences that have much more in common than different, mainly the fact that both involve irreversible changes in life conditions with limitations in daily routines and a decrease of adaptation potentialities, when compared to healthy peers. From a health psychological perspective, chronic disease includes all incurable diseases, or the ones with a long-term evolution, and the most relevant is the point of view of the subjective individual's experience (Barros, 2003).

2. Epidemiological Data

Currently, chronic health conditions affects 1 out of 6 children (van der Lee et al., 2007). According to the Centers for Disease Control and Prevention (CDC), chronic disease is the leading cause of death and disability in the United States, accounting for 70% of deaths and a high percentage of health care costs (CDC, 2016a). Data from the Non Communicable Diseases Global Status Report (WHO, 2014a) show that chronic diseases are by far the leading cause of premature mortality in the world representing 60% of all deaths, and in contrast to common perception, 80% of chronic disease deaths occur in low and middle income countries. Specifically in adolescence, asthma, epilepsy and diabetes, are some of the most prevalent chronic health conditions in adolescence (Barros, 2009; Yeo & Sawyer, 2005).

In Portugal, the evolution of infantile health is a success story acknowledged in the WHO Worldwide Report (WHO, 2008). The rate of infantile mortality decreased consistently and unexpectedly fast from 77.5% in 1960, to 3.6% in 2009 being the greater evolution of European countries (Machado, 2011). Once infectious diseases were controlled, clear gains were achieved for the first year of life; hence, it was important to focus on the health of children

and adolescents because other diseases, such chronic illnesses were emerging. As for adolescents in particular, there was an increasing concern to develop support within health care service facilities, to attend their specific needs and problems. A major focus was also directed to the effective transition to adult care, due to the large number of adolescents with a chronic disease growing into adulthood with physical, social, emotional and behavioural consequences, therefore, struggling with such changes (ACS, 2009). Since then, the acknowledgement of chronic condition in public national policies has raised (DGS, 2010a, 2013, 2015; OPSS, 2014), although it seems more focused on general recommendations and less on specific guidelines for the assessment, measurement and implementation of effective interventions concerning the psychosocial care.

Data from the National Institute of Statistics in 2011 indicated a prevalence of 19.9% of individuals between the age of 15 and 24 years old, that reported a health condition or a long-lasting disease (INE, 2012). In the study KIDSCREEN – Quality of Life and Health in Children and Adolescents (Matos et al., 2012b) conducted in Portugal in youths aged 11.5 years old, girls more frequently reported health problems compared to boys (18.5% *vs.* 14.6%) and 16.5% reported a chronic disease or long-lasting condition or disability diagnosed by doctor. From these group, 11.6% indicated that the disease affected their participation in school activities.

More recently, in the last survey of the international study Health-Behaviour in School-aged Children – HBSC/WHO conducted in Portugal in 2014 (Matos, Simões, Camacho, Reis, & Equipa Aventura Social, 2015), the results with youths aged 14 years old, showed that 17.8% had a chronic disease or long-lasting condition or disability diagnosed by doctor. Within this group, 16.9% felt that the disease affected their participation in school, 23.3% reported an impact in leisure time with friends, and 13.6% reported an effect on family activities. In addition 13.6% indicated that in the last four weeks the disease caused school absences once or three times (more than half of the day each time), and in the last year 14.9% had to be hospitalized once or three times. Finally, 15.1% reported the need of additional help from others in daily tasks. The most frequently reported chronic diseases were allergic diseases (52.9%), asthma (30.7%) and cardiac disease (4.7%), although diabetes (2.4%), epilepsy (2.3%) and arthritis (1.7%) also had a relevant frequency.

2.1. Diabetes, Allergic Diseases and Neurological Diseases

Facing the national data previously reported by HBSC/WHO, a brief description of some of the most frequently reported diseases will be presented and grouped in type 1 Diabetes *mellitus*, Allergic diseases and Neurologic diseases.

Diabetes *mellitus* describes a metabolic disorder of multifactorial etiology characterized by chronic hyperglycemia with disturbances of carbohydrate, fat and protein metabolisms, resulting from deficiencies in insulin secretion, insulin function, or both. Dysfunction, organ failure, long-term impairment and increased risk for microvascular/macrovascular complications are frequent effects of diabetes (WHO 1999). Hyperglycemia, or raised blood sugar, is a common effect of uncontrolled diabetes, and over time it can lead to serious damage in several body systems, especially the nerves and blood vessels. Type 1 Diabetes *mellitus* (sometimes known as insulin-dependent or childhood-onset diabetes) is a metabolic disorder of complex aetiology involving genetic and environmental factors (Eringsmark Regnell & Lernmark, 2013); the pancreas does not produce enough insulin thus its daily administration is required for survival. Type 1 Diabetes *mellitus* usually appears in childhood and adolescence with sudden onset and symptoms, including polyuria, excessive thirst (polydipsia), constant hunger, weight loss, vision changes and fatigue (WHO, 2015).

Allergic diseases can be defined as a dysfunctional immune-mediated hypersensitivity response to common environmental substances (Douglass & O'Hehir, 2006) and include life-threatening anaphylaxis, food allergies, certain forms of asthma, rhinitis, conjunctivitis, angiooedema, acute urticaria, eczema, eosinophilic disorders, including eosinophilic oesophagitis, and drug/insect allergies (Pawankar, 2014). Asthma is a major "non-communicable disease", but when compared to other chronic diseases, has a relatively low fatality rate. It is characterized by recurrent attacks of dyspnea and wheezing, varying in severity and frequency from person to person. Symptoms may occur several times in a day or week, and for some people become worse during physical activity or during sleep. An asthma crisis includes the swelling of bronchial/alveolar tubes, causing the airways to narrow and reducing the flow of air into and out of the lungs. Sleeplessness, daytime fatigue, reduced activity levels and school/work absenteeism are common consequences of recurrent asthma symptoms (WHO, 2013a). The most recent update of the Global Initiative for Asthma (GINA) report presents a consensual definition of asthma, considering it as a heterogeneous disease,

usually characterized by chronic airway inflammation and defined according to the history of respiratory symptoms (wheezing, shortness of breath, chest tightness and cough) varying over time and in intensity, along with variable expiratory airflow limitation (GINA, 2014).

Neurological disorders are diseases of the central and peripheral nervous systems; strictly speaking, the brain, spinal cord, cranial nerves, peripheral nerves, nerve roots, autonomic nervous system, neuromuscular junctions, and muscles. There are more than 600 diseases of the nervous system including epilepsy, Alzheimer's disease and other dementias, cerebro-vascular diseases including stroke, migraine and other headache disorders, multiple sclerosis, Parkinson's disease, neurological infections, brain tumors, traumatic disorders of the nervous system such as brain trauma, and neurological disorders as a result of malnutrition (WHO, 2014c). Epilepsy is a chronic disorder of the brain that affects people at all ages and, worldwide, it is one of the most common neurological diseases. It is characterized by recurrent seizures, which are brief episodes of involuntary movements that may involve a part of the body (partial) or the entire body (generalized), sometimes accompanied by loss of consciousness and control of large bowel or bladder sphincters (WHO, 2016b).

Type 1 Diabetes *mellitus* and the most prevalent diseases within the other groups - Asthma and Epilepsy - have biological differences, but also similarities in what concerns psychosocial challenges to adolescents. Asthma and Epilepsy have a more acute and relapse form, whereas Type 1 Diabetes *mellitus* generally has a gradual onset and life-long duration. Despite the biological diversity and according to the classification of Rolland and Walsh (Rolland & Walsh, 2006) all of them are non-incapacitating diseases. Additionally, they share the following characteristics: long-life course with episodes that can be life threatening (Leventhal, Halm, Horowitz, Leventhal, & Ozakinci, 2004), unpredictable progression with long-term dependency, adjustment to lifestyle behaviours, adherence to therapeutics/treatments and demand a strong commitment to self-management strategies (Kyngas, 2000). Furthermore, they all have in common a significant duration and potential long term impact on daily lives of youths and their families (Varni, 1983).

3. Adolescence and Chronic Disease

The Society for Adolescent Medicine stated that all individuals deserve to have appropriate services for their age and developmental stage (whether in primary preventive or tertiary care) (Morton & Westwood, 1997). Nevertheless, the previously discussed definition for chronic conditions considered the developmental period of childhood and mainly the ages from 0 to 18 years old (Mokkink et al., 2008), which seems a wide age range, including distinctive developmental stages, characterized by different maturational issues and developmental tasks that should be studied independently (Erickson, 1982; Sprinthall, Oja, & Sprinthall, 1998). Literature points out the need to analyses childhood and adolescence separately as single groups, due to age influences on health outcomes (Sawyer et al., 2004; Silva, Carona, Crespo, & Canavarro, 2015a; Varni et al., 2007). This fail to recognize adolescence as a specific developmental age group, lead to strong limitations in epidemiological data, by grouping adolescents with children (0-14 years old) or with adults (15-34 years old), resulting in national and international discrepancies (Saywer, Drew, Yeo & Britto, 2007a). A recent systematic review (1994-2014) concluded an inconsistent approach to age group specificities (Carona, Silva, & Moreira, 2015), and such scenario may difficult the implementation of better interventions for adolescents (Sawyer et al., 2007a).

The assumption that an age differentiation is needed rely upon the fact that adolescence comprises a transitional phase between childhood and adulthood, representing one of the critical transitions in the life span, characterized by a huge step in growth and change, the second one after infancy. It is a period of preparation for adulthood where several key developmental experiences occur. Physical/sexual maturation and important neuronal developments take place, responsible for the reward processing, emotional responses and executive functions (decision-making, organization, impulse control and future planning). Also psychological and social changes occur, namely an increase in cognitive and intellectual capacities, reasoning skills, logical and moral thinking, abstract thinking and rational judgements. Identity and personality, as well as the acquisition of skills to engage in adult relationships and social roles emerge (WHO, 2016a). Additionally, it urges an aim for more social/economic autonomy and independence to make individual choices and decisions, along with a focus shift from family to friends and peers (Meeus, Iedema, Maassen, & Engels, 2005). In summary, it is a unique period of discovery, experimentation and biopsychosocial transformations.

Several age ranges for adolescence can be found in the literature (**Table I-1**) and are presented below.

Table I-1. Different age ranges to define adolescence.

Organization/Theory	Ages (Years Old - Y)
WHO (WHO, 2016a).	• 10 to 19 Y
United Nations (United Nations, 2013).	• 15 to 24 Y
Erickson's stage developmental theory (Erickson, 1982; Sprinthall et al.,1998).	• 12 to 18 Y
DISABKIDS Group Europe (The DISABKIDS Group Europe, 2006).	• 13 to 18 Y
CDC (CDC, 2016b);	• young teens (12-14 Y) • teenagers (14-17 Y)
UNICEF (UNICEF, 2011).	• early adolescence (10–14 Y) • late adolescence (15–19 Y)

Although adolescence is a time of remarkable growth and potential, it can also be a moment of increased vulnerability, since youth start to move outside the family setting, and social contexts may exercise powerful influences. In addition, changes during this period can affect how adolescents think and act, and adolescence is, therefore, a critical developmental stage and an opportunity to set a positive course for adolescent's health and their future health and well-being addressing behaviours that can have significant repercussions throughout life, especially the path of chronic health conditions (Baldwin, 2013; WHO, 2016a).

Living with a chronic condition in adolescence, where profound bio-psycho-social changes occur, involves a whole set of new multifaceted challenges for the individual, his/her family and health care professionals (Michaud et al., 2007; Suris et al., 2004). It implies learning self-management strategies (Sawyer, Drew, & Duncan, 2007b), daily routines and functioning (for example: medications, adherence to treatments), adopting healthy lifestyles, monitoring symptoms (WHO, 2003), and dealing with uncertainty about the disease itself and the future. It is a demanding experience for adolescents that can affect several aspects of the individual's life, namely social, family and occupational functioning. In addition, it also involves the adjustment on multiple life domains, and the regulation of cognitions, emotions, behaviours, physiologic aspects and the interaction with others (Compas et al., 2012). Considering that friends and peers assume a major relevance for adolescents (Harter, 1990), to make changes in

lifestyles and routines can be quite difficult in the maintenance of group inclusion and also compromises the path for autonomy and independence from parents, that is typical of this age period. However, it must be taken into account the interaction and reciprocal potentially effects of chronic disease and adolescence, because the disease can affect developmental processes, but the contraire is also true, *i.e*., physiological and psychological changes can in turn have an impact on the disease (Suris et al., 2004).

Thus, the impact of a chronic diseases represents an additional burden for natural developmental challenges (Carona et al., 2013; Sawyer et al., 2007b) and health professionals report that disease management is more challenging in adolescence than in other groups (Veit, Sanci, Coffey, Young, & Bowes, 1996). The diagnosis, treatment and ongoing management of chronic diseases, is not only stressful for health professionals, but also for siblings and parents (Yeo & Sawyer, 2005; Suris et al., 2004; Michaud et al., 2007).

Chapter II

Health-related Quality of Life and Psychosocial Development in the Context of Chronic Disease

1. Relevance of Psychosocial Factors

Psychosocial is the shorthand term, combining psychological and social factors (Stansfeld & Rasul, 2007) and it has been widely used in literature related to health outcomes (Kojima et al., 2009). The roots of psychosocial health rely in the WHO's definition of health as "a state of complete physical, mental, and social well-being, and not merely the absence of disease and infirmity" (WHO, 1978). This conceptualization of health and the advances in medicine (diagnosis and treatment) conducted to discontent with the identification of disease burden focused on symptom reduction and survival rates (Bullinger et al., 2006; Varni et al., 2007). In result, a more holistic perspective for disease management and overall adaptation have emerged as central points of comprehensive healthcare and more positive adaptation indicators were established due to the prevalence of strength-based approaches in the health psychology in the past recent years (Ribeiro, 2009; Seligman & Csikszentmihalyi, 2000). The integration of physical health, social functioning and mental health (broadest sense and not pathological) were then considered as sensitive measures of the wide-ranging construct of adaptation (Wallander, Pit, & Mellins, 1990; Wallander et al., 1989). In fact, despite such an important and revolutionary idealistic concept of health, it was only in the decade of the 1980s that it was more put into practice, through a global perspective of both protection/promotion of health and prevention/treatment of diseases (Ribeiro, 2006), and started to be a relevant construct in the context of health/illness and in the field of health psychology (Leal, Pimenta & Marques, 2012; Leal, 2006; Ribeiro, 1998b; Ribeiro, 1994).

In order to continue daily life with a chronic disease, several behavioural changes have to occur. Beyond the biological aspects, the psychosocial experience is also relevant along with the individual representations of the disease (Ribeiro, 1998a). During development, and particularly in adolescence, participation in social activities and social peers connections are crucial because they assume a major importance in the socialization process (Sprinthal et al.,

1998), as protective factors (Maslow, Haydon, McRee, & Halpern, 2012) and may help coping with chronic disease (La Greca, Bearman, & Moore, 2002).

Thus, as a child advances in age, physical influences tend to diminish and psychosocial factors start to become more important (Gaspar, Ribeiro, Matos, Leal, & Ferreira, 2012). Theoretical models reinforced this idea, showing an association of multiple psychosocial factors with higher impact on adolescent's health (Simões, Matos, Lebre, & Antunes, 2014; Evans, Li & Whipple, 2013), and additionally, the adolescent-friendly health service concept (WHO, 2012) suggests the need to include physical, psychological, and social perspectives. Facing these evidence, clinical settings changed from mostly focusing on physical dimensions of the disease, and, the psychosocial development and well-being of adolescents with chronic diseases has been recognized and acknowledge (Combs-Orme, Helfinger, & Simpkins, 2002; WHO, 2013b; Marmot et al., 2012; Pulkki-Råback et al.; 2014; Watson, 2014). However, paediatricians frequently have limited training in this area (Geist, Grdisa, & Otley, 2003).

It was previously described that despite of the biological diversity, paediatric chronic diseases have several features in common, and as a group, an increased risk for psychological and social adjustment was found in the literature (Stein, Westbrock, & Silver, 1998; Wallander & Varni, 1998), resulting from a non-categorical approach on psychosocial development (based on the degree of burden of the disease and not on specific diagnosis) (Stein et al., 1993; Varni, 1983). Facing this homogeneous analysis it was important to have a standardized, generic measurement instrument to assess the impact of a chronic condition; the construct of HRQoL fitted this request (Varni, Seid, & Kurtin, 1999).

2. Quality of Life (QoL) and Health-related Quality of Life (HRQoL)

WHO defines QoL as "the individual's perception about its position in life, in the surrounding context of its culture and values systems, and in relation to its goals, expectations, standards and concerns" (WHO, 1997). It is a broad and generic concept that can be affected in a complex way by central dimensions determining QoL, such as the person's physical health, psychological state, level of independence, social relationships, personal beliefs and its association with the environment. It goes beyond direct measures of population health, life expectancy and causes of death, and focuses on the impact that health status may have on QoL

(WHOQOL Group, 1994). Several other definitions are also present in the literature comprising concepts related to well-being, happiness, satisfaction, expectations and functioning (Bramston, Chipuer & Pretty, 2005; Cummins, 2005; Meuleners, Lee, Binns, & Lower, 2003; Ribeiro, 2003).

HRQoL is a more restrict concept (Wallander, Schmitt, & Koot, 2001), characterized by being subjective, dynamic and unique (Cantrell & Kelly, 2015), and focused on the impact of health and illness on the individual's QoL and overall well-being (CDC, 2012; Payot & Barrington, 2011). It is generally conceptualized as a multidimensional construct comprising various domains of life, such as physical, psychological, mental, social and spiritual (Eiser & Morse, 2001), including family life, school performance and peer relationships (Ravens-Sieberer et al., 2005), and perceived by the patient and/or other observers (Bullinger, Schmidt, Peterson & Ravens-Sieberer, 2006). In addition, it also assesses goal attainment, financial implications (Cantrell & Kelly, 2015), functional/general aspects of well-being (Ravens-Sieberer et al., 2001; Ravens et al., 2005) and disease- and treatment-related symptoms (Varni, La Greca, & Spirito, 2000). The concept of HRQoL was introduced in healthcare as a specific component of the broader QoL construct, comprehending the subjective impact of health conditions, medical treatments and healthcare policies (De Civita et al., 2005). Considering that QoL has been conceptualized as a holistic concept, HRQoL is closer to the concept of "disease impact" and theoretically distinct from the QoL wide construct (although still related) (Wallander, Schimtt, & Koot, 2001).

The relevance of QoL and HRQoL in chronic diseases have been progressively recognized, given its implications for patients' well-being, results, planning of health resources and improvement of several skills required in a successful everyday life (Eiser & Morse, 2001; de Ridder, Geenen, Kuijer, & Van Middendorp, 2008; Gaspar, Ribeiro, Matos, Leal, & Ferreira, 2012; Suris et al., 2004). This is important because most of the children with chronic diseases have not and will not be cured, continuing to manage their illness into adulthood. Advances in biomedical science and technology continue to develop effective treatments and care, stressing out the relevance of measuring HRQoL as both a treatment and a health status outcome (Cantrell & Kelly, 2015). Self-assessed health status also proved to be a more powerful predictor of mortality and morbidity than many objective measures of health. Therefore, HRQoL questions about perceived physical/mental health and function, have become important

elements of health surveillance and considered valid indicators of service needs for interventions' efficacy (Payot & Barrington, 2011), enabling to address areas of healthy public policy (DeSalvo, Bloser, Reynolds, He, & Muntner, 2006).

To finish, it is important to note that along with HRQoL, other subjective health constructs (Currie et al., 2012; Matos & Equipa Aventura Social, 2000-2014) frequently appear in the literature. Although similar, they have distinct differences.

Subjective health, or **self-rated health** are important components in the WHO definition of health (WHO, 1948). These concepts ask the individual to reflect and evaluate his/her global health (Ravens-Sieberer et al., 2010c), taking into account the individual and social contexts, and it can vary according to individual conditions, such as age, gender, socioeconomic status and ethnicity (Blaxter, 1990). Self-rated health is a typical measure related to health-status (long-term dimension), whereas health complaints, injuries and accidents reflect a health-state (short term dimension) (Blaxter, 1989).

The multidimensional concept of **subjective well-being** is distinct from subjective health or self-rated health, because it comprises both emotional and cognitive components, that can be stable or passively to change over time (Diener, 1994). **Life satisfaction** is a measure that evaluates aspects of well-being that capture the emotional states in a particular moment in time (OECD, 2013), and in the sense that an individual judges his/her position in life (Diener, 1994; Ravens-Sieberer et al., 2010c). Life satisfaction is a term also used as a synonymous for well-being (Bjørnskov, 2008; Currie et al., 2008; Diener et al., 2003), and these both concepts are associated with positive health outcomes, such as mental health (Park, 2004).

3. Concerns in QoL and HRQoL Assessment in Adolescents

Despite the fact that HRQoL became a relevant concern amongst health professionals (Koot, 2002), the WHOQoL definition may not be directly applicable to the youth's QoL and well-being, and HRQoL's measurement in the paediatric population can be a challenging task.

3.1. Developmental Issues

When applied to youths, the adult-definition should value developmental changes (Varni et al., 2000) and an individualized approach to their concepts of health and illness, as

well as the inclusion of goals, aspirations and constrains imposed by the continuum illness-health and treatments (Taylor, Gibson, & Franck, 2008). Moreover, the WHO guidelines (WHO, 1993) recommend for the assessment of QoL in this population, the use of developmentally appropriate, cross-culturally comparable instruments and generic and specific assessment modules.

3.2. Highlighting Psychosocial Dimensions

As a child advances in age, physical and biomedical factors diminish their importance as determinants of self-perceived QoL, and psychosocial factors become relevant (Payot & Barrington, 2011). Thus, psychosocial variables can assume a crucial role, more than the presence *per se* of physical dimensions of the health condition (Denny et al., 2014; Mackner, Bickmeier, & Crandall, 2012; Olsen et al., 2012).

As a result, chronic disease's assessment should be less focused on diagnostic categories (where more variability exists), and more on the impact that the disease might have on the socialization process, emotional health and general limitations in ordinary activities (Denny et al., 2014; van der Lee et al., 2007). Supporting this idea, clinical settings have been progressively recognizing the need to complement traditional health indicators with psychosocial factors (WHO, 2013b; Watson, 2014), which requires a routine assessment in paediatric contexts (Clarke & Eiser, 2004). Moreover, to include such factors in clinical decision making and in research is necessary, because managing symptoms and improving psychosocial care are now primary goals of interventions (de Ridder et al., 2008; Marmot et al., 2012; Pulkki-Råback et al., 2015; Watson, 2014).

3.3. Self/Proxy-reports and Generic/Disease-specific Measures

Youths were often assumed as unreliable informants of their QoL and consequently, research used mostly proxies from mothers (Eiser, & Morse, 2001; Sawyer et al., 2007a). However, questions concerning who is the most likely best respondent for assessment (self- or proxy-reports) have been a growing topic in empirical literature that frequently found a *cross-informant inconsistency*, *i.e.*, lack of agreement among both reporters (Silva, Crespo, Carona, Bullinger, & Canavarro, 2015b; Varni et al., 2000). More specifically, a *disability paradox* was suggested, referring to clinical cases where mal-adjustment is greatly expected by external

observers, but not verified (and even contradicted) in self-reports (Albrecht & Devlieger, 1999; Carona, Moreira, Silva, Crespo, & Canavarro, 2014). Other studies suggest a greater congruence in older adolescents (15-17 years old), rather than younger (12-14 years old) (Youngblade & Shenkman, 2003), and less similarities between parents and adolescents concerning psychological health and behavioural needs (Youngblade & Shenkman, 2003; Verhulst & van der Ende, 1992). On the contraire, literature also pointed out that both parents and child tend to have consistent HRQoL self-perceptions (Gaspar, Matos, Batista-Foguet, Ribeiro & Leal, 2010a). Thus, self- and proxy- issues are still in need of further enlightening (Sawyer et al., 2007a).

Given that HRQoL is related with the individual's perception on the impact of diseases and treatment (Schipper, Clinch, & Olweny, 1996), this cross-informant variance puts forward the need to focus on self-report instruments for an accurate measurement. Therefore, in order to access information concerning adolescents' chronic health conditions and its impact on their lives, research has been gradually steering away from seeking opinion through proxy from parents or healthcare providers, and moving to ask adolescents directly, since there is evidence that they can provide a better explanation of their experiences (Sawyer et al., 2007a) and are described as competent interpreters of their "world" (Sartain, Clarke, & Heuman, 2000; Young et al., 2009). Also cognitive studies confirm the need to ask adolescents directly about their health, health-related needs and feelings (Mazur et al., 2013) and there has been an increasing relevance in "giving voice" to children/adolescents with chronic diseases (Varni et al., 2005), taking into account their needs, desires, knowledge, competences and rights (Michaud, Suris, & Viner, 2004). Furthermore, adolescents can help to complement quantitative data with qualitative crucial information (Zhang & Creswell, 2013), such as ideas to improve the instruments of assessment, medical/treatment procedures, clinical settings and social interaction with health professionals, teachers, parents and peers. Qualitative research can be useful to meet such goal (Fegran, Hall, Uhrenfeldt, Aagaard, & Ludvigsen, 2014), although it is still an emerging developing area. Thus, self-report assessment of individual's perceptions is recommended (von Mackensen, Campos, Acquadro, & Standberg-Larsen, 2013) and the WHO guidelines (WHO, 1993) also emphasize its use whenever possible.

Nevertheless, reliable and valid parent proxy-reports in complement to self-report are also important, since parents are the main responsible for clinical decision-making, clearly influencing the HRQoL's perceptions of their children (Carona et al., 2015; Eiser & Morse,

2001); moreover, they can better help to identify and encourage effective treatment and care (Varni et al., 2000). Such multi-informant approach allows having a dyadic comprehensive perspective of outcome assessment (White-Koning et al., 2007; Van Roy et al., 2010), and it is particular relevant in cases when the adolescent is unable or unwilling to make its own report (Varni et al., 2000). For that purpose, it can be considered an ecological perspective (Bronfenbrenner, 2005), which includes multiple levels of analysis, namely self-perceptions and family perceptions (Harding, 2001).

The choice of generic versus disease-specific instruments for adolescents with chronic disease is as relevant as in other populations. Generic measures facilitate the comparison between adolescents with different diseases *vs*. population norms. Disease- specific instruments facilitate comparisons within the same diseases, but for example, between children and adolescents or between adolescents and adults (Sawyer et al., 2007a). A systematic literature review conducted in 2004 reported little evidence of using these measures, and few studies have compared HRQoL with different diagnosis or groups of diseases. Even fewer studies were found determining changes over time as a function of disease stability (where age/maturational effects could be further explored), or instability (where interactions of age and health status could be addressed and explanatory mechanisms investigated) (Clarke & Eiser, 2004).

3.4. Aspects comprising HRQoL in Adolescents with Chronic Diseases

It is important to take into account that HRQoL's perception of youths can be influenced by several factors, such as age, gender, personal and family characteristics, and socioeconomic status (Houtrow, Jones, Ghandour, Strickland, & Newacheck, 2012; The KIDSCREEN Group Europe, 2006; Ravens-Sieberer et al., 2001; Ravens-Sieberer et al., 2005). These factors can be organized into two broad categories: personal and social that have a mutual influence (Gaspar et al., 2012). Personal factors include self-esteem, optimism, coping strategies, resilience and emotional management (Wrosch & Scheier, 2003), whereas, social factors mainly consist of social support (Gaspar & Matos, 2008; Gaspar, Matos, Ribeiro, Leal, Ferreira, 2009a; Helgeson, 2003). Social support is extremely important for development, has a relevant impact on positive health, well-being and HRQoL (Coventry, Gillespie, Heath, & Martin, 2004) and is related to adjustment and social skills, which seem to be protective factors against stressful live events (Boosman, Meulen, Geert, & Jackson, 2002).

4. Impact of Chronic Disease in HRQoL and in Psychosocial Development

Previously it was discussed that chronic disease is often characterized by great variability: in the definition of the concept, in the assessment of its prevalence, as well as in the identification of its impact on the child or adolescent (Denny et al., 2014). Apart from this variability, it is well recognized that it can represent a major psychosocial burden, and can contribute to the risk of a higher level of psychosocial stress (Sawyer et al., 2007a). Young people living with a chronic disease have to cope with a whole set of new multifaceted challenges, often face more difficulties negotiating the typical tasks of adolescence than their healthy peers (Perrin, Gnanasekaran, & Delahaye, 2012), and can be affected in their general development (Suris et al. 2004) and QoL (Kourkoutas, Georgiadi, & Plexousakis, 2010; Payot & Barrington, 2011). In addition, they can feel a high risk of impairment in their HRQoL's perceptions (Petersen-Ewert, Erhart, & Ravens-Sieberer, 2011), more specifically in the physical, cognitive, social and emotional dimensions (Bernstein, Soren, Stockwell, Rosenthal, & Gallagher, 2011; Varni et al., 2007; Verhoof, Maurice-Stam, Heymans, & Grootenhuis, 2012). Despite this recognition, the attempts to identify the degree of which physical and psychological well-being might be compromised have been mainly fallen into broad categories: studies predominantly focus on risk factors and risk-taking behaviours; others emphasizing more broadly HRQoL (Sawyer et al., 2007a).

Adolescents with chronic diseases can be more vulnerable to adverse health outcomes and be at a higher risk for a healthy emotional and psychological development (Saunders, 2011; Scaramuza et al., 2010; Suris, Bélanger, Ambresin, Chabloz, & Michaud, 2011). They can experience adjustment difficulties (Oeseburg, Jansen, Groothoff, Dijkstra, & Reijneveld, 2010; Geist et al., 2003), as well as internalizing symptoms, such as depression (Miyazaki, Amaral, & Grecca, 2006), anxiety, social withdrawal, and other externalizing-related behaviours (Lavigue & Fier-Routman, 1992). The effects of growing up with a chronic disease are also associated with worse HRQoL and symptoms of anxiety and depression in young adults (Verhoof, Maurice-Stam, Heymans, & Grootenhuis, 2013).

Moreover, the effects of a chronic disease extend beyond the individual level to the entire family system (Quittner, Romero, Kimberg, Blackwell, & Cruz, 2011; The KIDSCREEN Group Europe, 2006). In the case of chronic disease in adolescence, parents assume a relevant role of caregivers and disease managers (health protection behaviours), and concurrently they

also have to promote autonomy/responsibility in their children (Barros, 2009). Balancing these two opposing goals can be an extra effort for parents and represent a new learning skill (Santos, Matos, Simões, Camacho, Tomé, & Moreno, 2013). Due to disease-related factors the adolescent can be more functional and emotional dependent from parents, *vs.* healthy peers (Kasak, Segal-Andrews & Johnson, 1995), and have his/her autonomy compromised. Therefore, potentially conflicts with parents are more likely to occur (Herzer et al., 2010; Nagano et al., 2010).

Literature additionally indicated that parents of adolescents with chronic diseases are more protectors and put more restrictions to autonomy and independence, when compared with parents of adolescents without chronic diseases (Eiser & Berrenberg, 1995). Furthermore, research also suggested that a parental authoritative and non-helplessness style, is associated with high disease's control (Shorer, David, Schoenberg-Taz, Levavi-Lavi & Meyerovitch, 2011), low paediatric parental stress and benefits for familiar functioning and QoL of adolescents (Botello-Harbaum et al., 2008; Monaghan, Horn, Alvarez, Cogen, & Streisand, 2012).

Along with consequences in the family system, research suggested that a relevant impact of the disease could also be observed in the academic context (Boonen & Petry, 2012; Mackner et al., 2012), mainly through frequent school absences, poor academic performance and self-perceptions of academic competence, as well as difficulties to cope with classroom demands (Logan, Simons, Stein, & Chastain, 2008). Therefore, it may affect relationships with friends and may lead to isolation from the peer groups (Mazur & Małkowska-Szkutnik, 2010), with consequences on non-academic contexts such as health and well-being (Currie et al., 2012). These negative consequences place adolescents with chronic conditions at a higher risk for poor educational, vocational, and social outcomes (Määttä et al., 2013; Maslow, Haydon, McRee, Ford, & Halpern, 2011).

As age advances, and particularly in adolescence, participation in social activities, connections, and peers are crucial because they assume a major importance in the socialization process (Sprinthall et al., 1998). These factors also represent a powerful positive protective factor and a key component for developing healthy youth (Maslow et al., 2012) once peer relations and support from close friendships can play an important role in the adolescent's psychosocial development, and have a special significance mostly when a chronic disease

exists. Social connections can be a great help to cope with the disease, with the psychosocial changes, and with the lifestyle aspects of treatment regimens (La Greca et al., 2002). However, these same connections can also be a major challenge for treatment recommendations and for therapeutic adherence. This is because being healthy is important for "fitting in" with peers. Such participation in educational/social activities with peers, and the connections with other people/institutions, can be weakened due to various consequences of having a chronic disease in adolescence (WHO, 2002).

Facing the previous evidence it seems that research comparing adolescents with and without a chronic conditions, or among different conditions, has been ambiguous and inconclusive (Compas et al., 2012; Payot & Barrington, 2011; Verhoof et al., 2012). More specifically, the results on emotional well-being and psychosocial development of these adolescents are still ambiguous and variable, due to the definition of chronic disease (Mokkink et al., 2008; Villarreal-Rodríguez, Treviño-Garza, Mancillas-Adame, Martínez-Villarreal, & O-Cavazos, 2013), the intrinsic complexity of the disease state and the numerous instruments used to assess psychological well-being (Leung et al., 1997). In addition, reports generally focus on a single set of conditions, or on very large populations (Villarreal-Rodríguez et al., 2013).

Therefore, it is crucial to take into consideration that adaptation responses towards a chronic disease are heterogeneous and quite variable, depending on various specific individual/contextual factors and on the type of condition and emerging limitations (Barlow & Ellard, 2006; Lee et al., 2013). Furthermore, an association with worse QoL and the type of chronic condition can be observed, as well as when there is prevalence of different health conditions and a higher number of concurrent health problems (3 or more compared with 2) (Barros et al., 2008; Lee et al., 2013; Sawyer et al., 2002). Therefore, cumulative risks may have a strong impact and may be a threat to the adolescent's well-being, particularly in the emergence of psychological symptoms (Simões et al., 2014).

5. Determinants of QoL and HRQoL in Adolescents with Chronic Diseases

The individual perception-related disease and the adaptation to a chronic condition is a dynamic and changeable process, and it can be modulated by the child's age, gender,

corresponding socio-cognitive developmental level (Holden, Chmielewski, Nelson, & Kager, 1997), real perception, exposure to cultural/familiar beliefs (Barros, 2003) and construction of concepts of health and illness (Taylor et al., 2008). Thus, interpretation, comprehension and meanings associated with the impact of chronic condition are strongly affected by culture and socialization processes, influencing its integration in the adolescent life's context (Barros, 2003).

Cross-cultural data suggest that life satisfaction and better health are associated with financial satisfaction (Oishi, Diener, Lucas, & Suh, 1999), socioeconomic status and education, that are in turn strongly associated with several chronic diseases (Olén, Bihagen, Rasmussen, & Ludvigsson, 2012), influencing directly and indirectly health status and self-perceived health (Borges, Matos & Diniz, 2011; Matos, Simões, Batista-Foguet, & Cottraux, 2010). In almost all 22 European countries, groups of lower socioeconomic status have shown higher rates of death, poorer health self-assessments (Currie et al., 2012; Mackenbach et al., 2008), prevalence of subjective health problems and poorer health (Richter et al., 2009; Torsheim et al., 2004). Adolescent's self-rated health, reported mental health and QoL, also decline significantly, especially in low/middle-income families (Cui & Zack, 2013; Zashikhina & Hagglof, 2013) and mental and physical childhood health outcomes have persistent effects on lifetime health and socioeconomic status outcomes (Currie, 2009). Thus, literature points out that older pupils, girls, students with low socio-economic status, or frequent health complaints can reported decreased mental health (Erhart et al., 2009) and HRQoL (Gaspar et al., 2009a). In Portugal, the studies Health Behaviour School-Aged Children – HBSC (Matos & Equipa Aventura Social 2000-2014) and KIDSCREEN (Gaspar & Matos, 2008; Matos et al., 2012b), have shown the same tendencies (poorer health and life satisfaction in girls and older adolescents), suggesting higher vulnerability in this population.

Concerning gender in particular, the literature underlined a tendency for girls, when compared to boys, to report poorer health outcomes (Määttä et al., 2013), and higher risk in various domains, namely in psychological symptoms (depression and anxiety) (Suris, Parera & Puig, 1996) and life satisfaction (Currie et al., 2012). Different internalization and externalization patterns as well as gender-specific puberty experiences, can play an important role to explain such findings (Cavallo et al., 2006).

Despite divergent results in the field of chronic diseases, literature has highlighted some determinants comprising HRQoL, which can be divided into two factors: disease-related factors, (age of onset, disease severity, complications, treatment, sense of normal and positive attitude towards the disease), and non-disease-related factors (age, gender, socioeconomic status, support of parents, social wellbeing and support (Sawyer, Spurrier, Kennedy & Martin, 2001).

6. Challenges for Health-related Behaviours: Protection and Risk Factors

Measuring HRQoL aims to capture the individual's subjective perception of health and illness. However, due to diversity of conceptualization of chronic disease, well-being, QoL, HRQoL, subjective health constructs and it's outcomes in adolescents, the concept of "health as a state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity" defined in 1948 by the WHO (WHO, 1948), need to have a dynamic conceptual framework when applied to chronic diseases. More recently, a more positive perspective of health was assumed and within the context of health promotion, it has been seen less as an abstract state, and more as a mean to achieve an goal, which, in functional terms can allow people to have an individually, socially and economically productive life. Thus, considering health as a resource for everyday life, not the object of living, is a positive concept emphasizing social and personal resources as well as physical capabilities (WHO, 1986). Such idea was also reinforced in the literature that assumes health as the ability to adapt and to self-manage (Huber et al., 2011). Therefore, despite the relevance of the assessment of HRQoL, research suggests that some difficulties emerge from such measure, e.g. the difficulty to address the dynamic process of experiencing health in the context of a chronic disease (and in the life course), and to reflect the individual performance and functioning (Bowling, 1997; Pollard & Davidson, 2001).

Having a moderate (or even high) result in HRQoL may not fully indicate a successful transition or the daily efforts to deal with adaptive tasks and stressors, that chronic diseases constantly demand to adolescents. In fact, the adaptation responses to the disease rely on the dynamic relationship between the adolescent, his environment (Houtrow et al., 2012), and psychosocial variables (Denny et al., 2014; Mackner et al., 2012). To better understand the

meaning of growing up with a chronic disease, it is crucial to address protective factors that may be underneath the adjustment process. Protective factors refer to conditions that improve people's resistance to risk factors and disorders (Coie et al., 1993), which can be, for adolescents with chronic disease, the diagnosis itself, the connections with the family, community, or relationships with peers (Nylander, Seidel & Tindberg, 2013).

The adolescent development involves experimental behaviours that can be understood as a normal part of teenage development (Steinberg, 2004). In youths with chronic disease, such exploring behaviours have historically assumed a protective role, helping to restrict opportunities that lead to risky behaviours (Frey, Guthrie, Loveland-Cherry, Park & Foster, 1997). However, research changed this perspective suggesting that adolescents with chronic diseases are doubly disadvantaged: first, they can engage in risky behaviours in a similar (if not higher rate), than healthy peers (Blum, Kelly & Ireland, 2001; Sawyer et al., 2007a; Suris, Michaud, Akre & Sawyer, 2008; Suris & Parera, 2005); and second, they are more vulnerable to the adverse health outcomes of these risky behaviours due to the disease (Kakleas, Kandyla, Karayianni & Karavanaki, 2009; Saunders, 2011; Scaramuzza et al., 2010).

Literature also evidenced that health/risk behaviours tend to cluster together (Suris et al., 2008; DuRant, Smith, Kreiter & Krowchuk, 1999; Rhee, Yun & Khang, 2007). Thus, increasing the understanding of protective factors in adolescents with chronic diseases assumes a major importance and the most relevant protective factors will be briefly described.

6.1. Resilience, Self-regulation and Social Support

Regarding psychosocial variables and considering The Assets Model (Morgan & Ziglio, 2007) it is important to pay attention to protective factors underlined in the literature on chronically ill adolescents, that can predict positive health outcomes, help cope with the disease and improve coping skills (Maslow & Chung, 2013), such as resilience (Helgeson, Reynolds, Siminerio, Becker, & Escobar, 2014; Hilliard, Harris, & Weissberg-Benchell, 2012; Matos et al., 2012a; Simões, Matos, Tomé & Ferreira, 2008), self-regulation (Gois et al., 2012) and social support (Wu, Geldhof, Roberts, Parikshak, & Amylon, 2013).

Resilience focus on the mediating mechanisms for risk and protective factors. It can be defined as a successful adaptation and outcome in spite of having experienced serious stresses or adversities (Rutter, 2013; Windle, 1999) and it is the ability to overcome physical disabilities

and develop social and relational skills (Payot & Barrington, 2011). To identify the irreversible aspects of the chronic disease, allowing the adolescent to deal with the new reality, seems to improve well-being and HRQoL. This appears to be a universal psychological response to adversity foreseeing that adaptation to a chronic disease requires a certain degree of acceptance (Payot & Barrington, 2011), but while facing challenges, some youth struggle, whereas others do not. To learn practical and clinically relevant strategies from resilient adolescents can better help planning psychosocial care for those that struggle (Hilliard et al., 2012), and resilience seems to be a promising candidate for interventions designed to reduce stress and improve outcomes (Guilera, Pereda, Paños, & Abad, 2015; Helgeson et al., 2014; Yi-Frazier et al., 2013).

In psychology, the **Self-regulation** concept considers the self as an active participant. Thus, the individual is self-regulatory once he/she meets or adjusts his/her behaviours in the presence of obstacles, while pursuing a long-term goal or desired state (Carver & Scheier, 1998). This ability is a bi-directional regulation process with the surrounding context and it is progressively developed during childhood and adolescence (Gestsdottir & Lerner, 2008; Zimmerman, 2002). It seems that a better adjustment occurs when the individual seems to clearly separate himself from his body, considering the disease just as one more thing that it is part of his/her life (Gois et al., 2012).

Social Support has been one of the most frequently studied concepts in the context of health and chronic diseases, both as a coping resource and as a protective factor (Decker, 2007). Along with subjective well-being, it comprises the factors reported to promote positive health in children and adolescents (Gaspar & Matos, 2008; Gaspar, Ribeiro, Matos, Leal & Ferreira, 2009b; Helgeson, 2003). Social support can be considered as the mechanism of interpersonal relationships and strategies that provide a good adaptation to new potentially stressful situations, reducing the tension and sense of control (Bertero, 2000; Gaspar et al., 2012). Adolescents with higher levels of perceived support tend to report fewer health complaints, depression and behaviour problems, and greater positive health practices, optimism, self-esteem (Decker, 2007), and better adjustment to disease (Varni, Katz, Colegrove & Dolgin, 1994).

Chapter III

Conceptual Models Related to Chronic Diseases

Evidence-based research presented an extensive variability in the processes of adaptation to a chronic disease in paediatric contexts (Barlow & Ellard, 2006), suggesting an important reflection on why some youths have a successful adaptation, while others struggle with it (Bradford, 1997).

Aside from models mainly based on deficit and limitations (who tried to address this question), paediatric psychology may bring a different insight into this complex mechanism. Paediatric psychology is the common designation for the subarea of health psychology that focuses on children and adolescent's health. It includes scientific research with clinical practice, and it appeared due to the recognition that psychological (behavioural, cognitive and emotional) factors are relevant to youth's health (Barros, 2003). Using this conceptual framework, research started to focus on the identification of risk and resilience psychosocial factors related with differentiated adaptation processes (Eiser, 1990; Wallander & Varni, 1998). The most relevant selected models related with the theme of this research will be briefly described.

1. The Socio-Ecological Model of Human Development

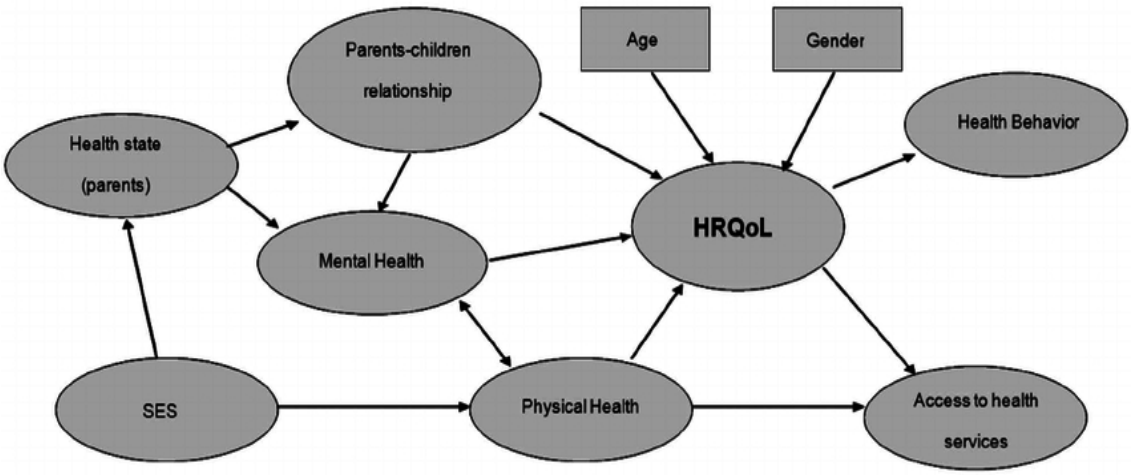
This model implies an ecological perspective and proposes a comprehensive hierarchical structure with multiple levels of analysis, which influences bi-directionally the child/adolescent. It is represented by concentric circles; each one contained in the next, and includes the following structures: microsystem, mesosystem, exosystem and macrosystem (Bronfenbrenner, 1977; 2005). The microsystem is the closest system to the child and the one where direct contacts occur (typically includes family, peers, caregivers, school). It is a bi-directional system and it's the most influential level of the ecological systems theory.

This model takes into account that the development of an adolescent with a chronic disease is influenced by their proximity settings and also by the external settings that have an indirect impact on his/her development (Silva, 2015).

2. The KIDSCREEN Model

The KIDSCREEEN model states that health behaviour and physical, psychological and social health aspects can influence HRQoL's dimensions in children/adolescents (The KIDSCREEN Group Europe, 2006). Conceptually the KIDSCREEN instruments are based on the definition of HRQoL as a multidimensional construct covering physical, emotional, mental, social and behavioural components of well-being and functioning as perceived by patients and/or other individuals. Furthermore, they are generic HRQoL measures that can be use in both healthy and chronically ill populations. This model is presented in **Figure III-1** (The KIDSCREEN Group Europe, 2006, pp.33).

Figure III-1. KIDSCREEN Model



3. The Disability-Stress-Coping Model

In the past decades, various conceptual models made an effort to explain how psychosocial factors (risk and resistance ones) interact to determine individual adaptation outcomes in the context of chronic diseases.

The Model of Crisis of Physical Illness (Moos & Schaefer, 1984) and the Model of Child Adjustment to Chronic Disease (Lipowski, 1970; Pless & Pinkerton, 1975) can be underlined and they both have common characteristics. First, they assume that the psychosocial consequences of chronic disease are less different than similar across nosological categories (Stein & Jessop, 1982), once relying on a non-categorical approach, therefore common to various chronic diseases and disabilities. Second, they considered that an unsuccessful

adaptation is not necessarily the result of living with chronic disease or disability. This balance depends on the capacity to manage potentially stressful events and lead to different adaptation outcomes. Third, they highlighted the interaction between personal competence (e.g., personality, self-concept) and socio environment (e.g., family characteristics, social support), to determine coping responses and adaptation outcomes.

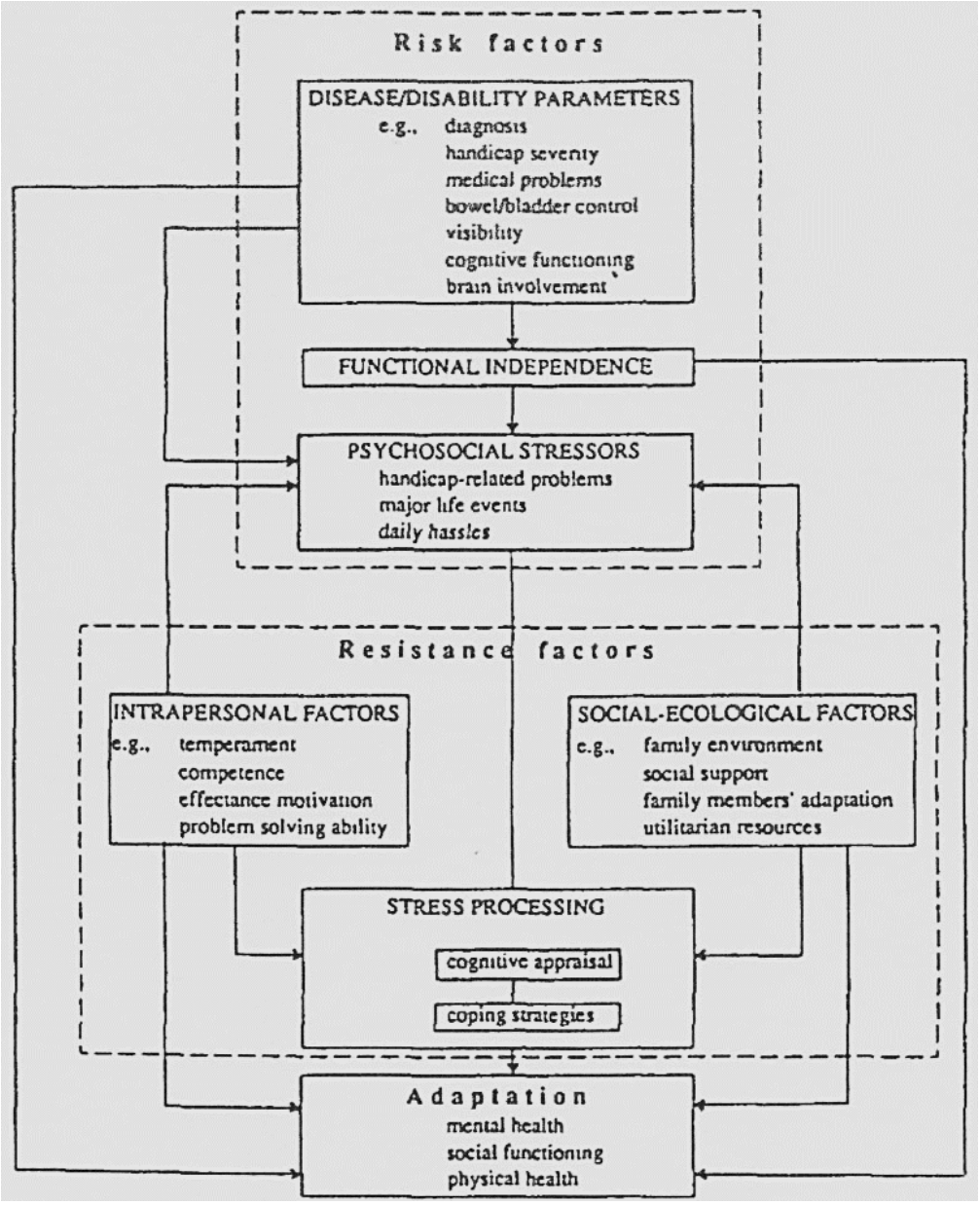
Later, another model was proposed, the Disability-Stress-Coping Model (Varni & Wallander, 1988; Wallander, Varni, Babani, Banis, & Wilcox, 1989) that integrated the previously described two models and dispersed empirical evidence, consisting of a coherent model to address the differentiated psychosocial adaptation in chronically ill and handicapped children in terms of risk and resistance factors. Disease or disability parameters, functional independence, and psychosocial stress were considered major risk factors and resistance factors and were also included (Wallander et al., 1989). This inclusion was based on the evidence that different chronic diseases/disability parameters did not have a significant association with behavioural adjustment (Wallander, Hubert & Varni, 1988; Wallander et al., 1989), thus, they could be moderately predictive of the children's social adaptation. However, the authors suggest that more investigation on whether disease parameters have an indirect effect on adjustment, is needed (Wallander et al., 1990).

Specifically, the Disability-Stress-Coping-Model underlines that the impact of risk factors (such as disease-related aspects, functional independence) is moderated by three main categories of resistance factors: intrapersonal resources, social-ecological factors, and stress processing mechanisms. It also indicates specific direct and indirect pathways through which risk and resistance factors may influence adaptation outcomes (Silva, 2015). The variables identified as resistance factors can be conceptualized both as a resource (such as variables that positively influence outcomes despite adversity), and/or protective factors (such as variables that reduce the probability of negative outcomes under adverse conditions) (Rose, Holmbeck, Coakley, & Franks, 2004). Considering the General Stress and Coping Model (Lazarus & Folkman, 1984), the impact of risk and resistance factors can be mediated by stress processing mechanisms that include the cognitive appraisal of a particular situation as stressful and the evaluation of available resources, which will determine the use of coping strategies.

Given the complexity of this model, the authors indicate that it not possible to entirely test it, instead, they suggest that small groups of variables/components or sub-models can be used

(Wallander & Varni, 1998). This model has several strengths such as the use of a non-categorical approach (applicable to any chronic disease), the identification of specific risk and resistance factors and the conceptualization of adaptation in line with the construct of QoL (multidimensional comprising physical, mental and social functioning) (Wallander & Varni, 1998). Nevertheless, a limitation in this model refers not to take into consideration developmental stages (Silva, 205). Therefore, in the Phases I and III of the present research, variables from resilience and risk factors were selected in an attempt to focus on sub-models for the associations between chronic disease and QoL/HRQoL and psychosocial factors. The Disability-Stress-Coping Model is presented in **Figure III-2** (Wallander et al., 1989, pp. 171).

Figure III-2. The Disability-Stress-Coping Model



Chapter IV
Concluding Remarks

This succinct introductory theoretical framework brings an overview of the present state of the art concerning HRQoL and psychosocial factors (and inherent adaptation process) in adolescents with chronic disease. It allows the identification of some research gaps and limitations, as summarized next.

Facing a chronic disease in adolescence is not an easy task. The disease can impact HRQoL and psychosocial development and literature has highlighted specific factors considered as protective for health outcomes (resilience, self-regulation and social support). Therefore, it was necessary to increase the knowledge in this field in Portuguese adolescents, as a complement of the results already found in previously conducted studies.

At the beginning of this research project and dissertation, to our knowledge, only a few number of studies addressed the associations between chronic disease and HHQoL and psychosocial outcomes in the specific age group of adolescents. This is particularly important because adolescence is a distinctive age period with specific developmental tasks that need to be studied independently (Carona et al., 2015; Erickson, 1982; Morton & Westwood, 1997; Sprinthall et al., 1998; Varni et al., 2007).

Furthermore, as a child advances in age, physical and biomedical factors diminish their importance as determinants of self-perceived QoL, and psychosocial factors become relevant (Payot & Barrington, 2011), assuming a crucial role (Denny et al., 2014; Gaspar et al., 2012; Mackner et al., 2012; Olsen et al., 2012). In addition, the existing research has yielded controversy findings regarding the impact of the disease on these variables, mainly due to several definitions of chronic disease and measures of HRQoL assessment (Mokkink et al.2008; van der Lee et al., 2007; Varni et al., 2007).

Thus, by acknowledging the current context, and the above mentioned research gaps, the present thesis attempts to gather some knowledge about the possible effects of chronic disease in HRQoL and psychosocial development, in particular in adolescents (both in a national representative level and in clinical population). Furthermore, using the point of view of the subjective individual's experience based on health psychology's perception (Barros, 2003), and having the theoretical guidance of a socio-ecological framework (Bronfenbrenner,

1977; 2005), the KIDSCREEN's model (The KIDSCREEN Group, 2006) and strength-based approaches (Eiser, 1990; Ribeiro, 2009; Morgan & Ziglio, 2007; Wallander & Varni, 1998), namely the Disability-Stress-Coping-Model (focused on the identification of risk and resistance psychosocial factors) (Wallander et al., 1989).

In the following chapters the aims and methods of the research will be described and findings presented and discussed. The conclusions and future implications intend to help future research, clinical practice and public health/education policies in their arrangements and actions, that can positively contribute to improve health outcomes, effective interventions and achieve holist psychosocial care in these adolescents.

Chapter V
Objectives and Methods

1. Research Objectives

The general aim of this study was to contribute to increase the knowledge on the impact of chronic disease on HRQoL and psychosocial factors in Portuguese adolescents. Associated with this general aim, three specific aims were proposed for this study, addressed in nine articles that form the scientific and empirical basis of this thesis. The specific aims were developed to address the purpose of this thesis, namely to have both a national representative and clinical sample and the use of subjective individual's experience and theoretical models. Accordingly, the specific aims are outlined below:

1. To explore and characterize the psychosocial functioning of Portuguese adolescents with chronic disease, through the analyses of the HBSC/WHO-Portuguese Survey 2010, aiming to increase the knowledge of Portuguese reality in a national-representative level.

2. To clarify possible associations between living with chronic disease and the impact on QoL/HRQoL and psychosocial factors, particularly in the specific age group of adolescence; and also potential influencing variables for outcomes;

3. To explore and characterize the impact of chronic disease on HRQoL and psychosocial factors, including protective ones reported in the literature, more specifically in a clinical population of Portuguese adolescents, in an outpatient department in a hospital context.

The **1st specific aim** was addressed in four empirical studies (empirical studies 1, 2, 3 and 4). These studies were preliminary and mainly exploratory, aiming to clarify the psychosocial impact of living with a chronic disease in Portuguese adolescents, in a national representative level. Article 1 and 2 focused on the impact of chronic condition at an individual-level basis: article 1 focused on wellness perception and life satisfaction, whereas article 2

emphasized psychological well-being, through self-reported psychological symptoms. Articles 3 and 4 studied the impact of chronic disease in a contextual-level basis: article 3 addressed satisfaction with family environment, perception of school competence and feeling pressure with schoolwork, while article 4 highlighted the association with health and risk/protection-related behaviours.

The **2nd specific aim** was addressed through a systematic literature review of 18 published research articles (2010-2015), reporting on associations between living with a chronic disease in adolescence and the impact on QoL/HRQoL and psychosocial functioning. Study features, research designs, participant's characteristics, control condition/comparison group composition, outcome measures and main findings were detailed explained (scientific study 5).

The **3rd specific aim** was addressed in four studies (empirical studies 6, 7, 8 and 9). Article 6 characterized HRQoL and psychosocial functioning in adolescents taking into account different diagnoses. Article 7 highlighted the associations of chronic disease with key psychosocial factors and school/peer connectedness. Article 8 identified the impact of chronic disease in the several dimensions of HRQoL and on key psychosocial factors, in a gendered way. Finally, article 9 analysed the impact of clinical and psychosocial factors on adolescent's HRQoL.

A summary of the main objectives for each scientific study is displayed in **Table V-1**.

Table V-1. Main objectives for the scientific studies

Scientific Study	Main objectives
1	To characterize adolescents: • Living with a chronic health condition; • Living with a chronic health condition and feeling that it affects school participation; and its association with life satisfaction and wellness perception (item "Feeling so sad that it seems that I can't take it"), controlling for demographic factors: age, gender and family socioeconomic status (SES) (FAS: Family Affluence Scale).
2	To explore the links between adolescents' psychological well-being and: • Living with a chronic health condition; • Living with a chronic health condition and feeling it affects/not affects school participation. Based on the literature it is expected that adolescents with chronic conditions report higher vulnerability in psychological well-being.

3	To characterize adolescents: • Living with a chronic health condition; • Living with a chronic health condition and feeling that it affects school participation and its association with satisfaction with family environment, "Feeling pressure with schoolwork", and "Perception of school competence". The demographic factors studied within these variables are age, gender and family SES by a proxy (FAS: Family Affluence Scale).
4	To characterize adolescents: • Living with a chronic health condition; • Living with a chronic health condition and feeling that it affects school participation; and its association with health and well-being related risk/protection behaviours, such as "drunkenness", "physical fight in the last year", "sadness" and "self-harm".
5	• To examine the main sources and types of evidence in recent literature focusing on the possible association between living with a chronic condition in adolescence and the impact on quality of life (QoL), health-related quality of life (HRQoL) and psychosocial functioning. • Specifically, to identify and summarize the most frequently addressed outcomes in literature referring to the risk of impairment in QoL/HRQoL and in psychosocial functioning, and to determine possible research needs.
6	• To make a psychosocial characterization of a group of adolescents with chronic diseases; • To compare the study's variables within the total group and in the three chronic disease groups, which were divided according to medical condition.
7	• Identify differences in psychosocial variables (health-related quality of life, psychosomatic complaints, resilience, self-regulation and social support) among adolescents who feel that chronic disease affects or does not affect participation in school (PSCH) and participation in leisure time with friends (PLTF); • Assess the extent to which psychosocial variables were associated with affecting or not affecting both areas of participation; • Identify the most relevant ones as well as those most amenable to intervention.
8	• Identify the impact of living with a chronic disease in adolescence, in the several dimensions of HRQoL and in key complementary psychosocial variables (psychosomatic complaints, resilience, self-regulation and social support); • Assess the extent to which psychosocial variables were associated with the several dimensions of HRQoL, analysing gender differences moderating those associations.
9	• Measure the impact of clinical and psychosocial factors (separated and combined) on the HRQoL of adolescents with chronic health conditions; • Identify the most relevant clinical and psychosocial variables that could help planning interventions, thus, increasing the knowledge on the impact of living with a chronic disease in adolescence.

2. Methods: General Description

The present research and its aims were conducted in three different phases, briefly described below.

Research Phase I addressed the **1st specific aim** of this thesis by exploring and characterizing the psychosocial functioning of Portuguese adolescents with chronic diseases, through the analyses of the HBSC/WHO Portuguese Survey conducted at a national representative level in 2010.

The characteristics of the HBSC's study itself, specifically being collected in the general population and in a school context, inspired the goal to better analyse the impact of chronic disease in adolescents, specifically in a clinical context (hospital), where more objective measures of disease are applied. In order to organize and plan such assessment, a clarification of the association on the impact of chronic disease on HRQoL and psychosocial factors in this particular age period, was required. For that purpose, a **Research Phase II** was conducted, addressing the **2nd specific aim** of this thesis through a systematic review of the current literature on QoL/HRQoL and psychosocial factors of adolescents living with a chronic health condition.

Finally, in **Research Phase III** moved by the insights obtained in the systematic review, and considering health recommendations and theoretical models, the **3rd specific aim** of this thesis that explored and characterized the psychosocial functioning of Portuguese adolescents with chronic diseases in a clinical context, was addressed. This phase used a comprehensive and multi-dimensional approach, aiming to achieve a better explanation of the differential psychosocial outcomes (including socio-ecological, intrapersonal and physical questions) (Wallander et al., 1988, Wallander et al., 1989). Data was collected in a clinical context in adolescents with chronic diseases mainly from Lisbon, Portugal, and three chronic frequently reported diseases were chosen: Type 1 Diabetes *mellitus*, Allergic diseases (including Asthma) and Neurological diseases (including Epilepsy). This choice was based on the literature (Barros, 2009; Yeo & Sawyer, 2005), on the national frequency rates according to the study HBSC/WHO (Matos et al., 2015), and on the availability of access to these adolescents in the clinical context. It is noted that disease specific characteristics or associated comorbidities were not in the focus of the present thesis.

In the following pages, the specific methodology (study designs, participants and general procedures) for the Research Phase I and Research Phase III will be described. The specific methodology of Research Phase II is presented in more detail in the respective Methods of the scientific article 5 (Part II-Systematic Review and Empirical Studies, Chapter VII).

3. Methods: Research Phase I - HBSC/WHO

3.1. Study Design

The Health Behaviour in School-Aged Children (HBSC/WHO) (www.hbsc.org/) is a World Health Organization (WHO) collaborative study that assesses school-aged children's health, well-being and their determinants in 44 countries in North America and Europe (Currie et al., 2012; Currie et al., 2014). The main goal of HBSC/WHO is to help inform policy makers on how to improve young people's lives and it is essentially descriptive, cross-sectional and correlational in nature, and pretended to assess children and adolescents mental and physical health (Currie, Samdal, Boyce, & Smith, 2001; Roberts et al., 2009). It also intends to better understand health behaviours and well-being among adolescents within their social context (Roberts et al., 2007), and provides a unique opportunity to assess the subjective health and well-being among children and adolescents using multiple indicators. The HBSC study includes a *Chronic Condition Optional Package Items* (Mazur et al., 2013), aiming to address the experiences of young people with chronic diseases and special educational needs.

All countries participating in the HBSC/WHO study followed a standardized research protocol (Griebler, Molcho, & Samdal, 2010). In Portugal, this survey is conducted every four years, since 1996 (Matos, & Equipa do Projecto Aventura Social, 2000-2014), by *Aventura Social* research team and is coordinated by its principal investigator Professor Dr. Margarida Gaspar de Matos from the University of Lisbon.

The four first empirical articles of this thesis used data from the Portuguese HBSC/WHO survey study 2010 (empirical studies 1-4).

3.2. Ethics

The HBSC/WHO Portuguese study followed all the rules for research outlined in the Declaration of Helsinki (WMA, 2008) and was approved by the Portuguese Ministry of

Education and Health, by the scientific committee, national ethics committee (*Hospital São João,, Porto/*São João Hospital, Oporto) (*vide* Part IV-Annexes, Chapter XIV) and national data protection. All participating schools gave their consent and made available informed parental consent, required by the committee of parents from each school. Confidentiality was ensured with anonymous response to the questionnaire and restricted access to HBSC research team members, regarding the work on computing and data analysis. These procedures are in agreement with the international standard guidelines from the HBSC/WHO survey protocol (Griebler et al., 2010).

3.3. Participants

This study HBSC 2010 Portuguese Survey (Matos et al., 2012c) included 5050 Portuguese adolescents (52.3% girls) with a mean age of 14 years old (*SD*=1.85), attending the 6^{th}, 8^{th} and 10^{th} grades, randomly selected from 256 classes and 125 national public schools, mostly with Portuguese nationality (94.4%), and not having a chronic disease (81%). Within the subgroup of chronically ill adolescents (19%), the majority indicated that the disease does not affect their regular participation and attendance in school (85.7%).

3.4. Procedure and Instrument

Data was collected in 139 schools, randomly selected from the official national list of public schools and stratified by region. In each school, the class was the analysis's unity, and classes were randomly selected in order to meet the required number of students for each grade. Questionnaires were sent to schools and, according to the protocol (Griebler et al., 2010), teachers administered the questionnaires in the classroom, with voluntary student participation. The response rate was of 90% regarding schools. No pupil's refusal was identified.

Especially designed to be appropriate for adolescents with age range of 11-15 years old, this survey consists of 75 items measuring background factors (e.g., socioeconomic status, family structure), individual and social resources (e.g., body image, school environment), health behaviours (e.g., smoking, dieting, sexual behaviour, violence), and health outcomes (e.g., life satisfaction, psychological well-being, and self-reported health). For the current dissertation, only some variables from HBSC were selected for the analysis. Due to the standardized international research protocol the digital version of the questionnaire cannot be presented, and for further information it is suggested to contact with the *Aventura Social* research team.

In this Phase I, first, comparisons between adolescents having/not having a chronic disease were performed, and, afterwards, within the chronically ill subgroup, between adolescents feeling affected/not affected in their participation and regular attendance at school (PSCH).

3.5. Measures

For the purpose of the present dissertation, in this Research Phase I only the selected variables presented in **Table V-2** were included in the four empirical articles (studies 1-4). With regard to the Chronic Condition Optional Package Items (HBSC/WHO) (Mazur et al., 2013), in the present thesis and for a shorten term, the item "Feeling that the disease affects/does not affect participation and regular attendance in school" (PSCH), will be also referred as school participation. In the following description, the selected variables were grouped by individual/psychological level and socio-contextual level, and also inspired by the HBSC/WHO structure (Currie et al., 2012; Matos & Equipa Aventura Social, 2000-2014).

Individual-Psychological Level

- ***Health Outcomes (empirical studies 1, 2):***

  Life Satisfaction (studies 1, 2). This outcome was measured with a Cantril's Self-anchoring Ladder (Cantril, 1965), a single item measure, where adolescents rated their current satisfaction with life. Specifically, they were asked to indicate on the ladder where they were at that time (0 was the worst possible life; 10 corresponded to the best possible life). Life satisfaction is a common key indicator of a persons' subjective well-being (Diener, 1994; OECD, 2013) and it has been validated and used in several studies, to assess different variables with mental health in adolescents (Cavallo et al., 2015; Diener, Suh, Lucas, & Smith, 1999; Muldon, Levin, van der Sluijs, & Currie, 2010).

  Wellness Perception (assessed by the Item "feeling so sad, that it seems that I can't take it") (studies 1, 2). This measure was included in the HBSC/WHO survey of 2010 after being pilot-tested and revised by a panel of experts from the *Aventura Social* research team (Matos, Gonçalves, Gaspar, & Equipa do Projecto Aventura Social, 2005). It was based on the self-reported Symptom's Check-List and in subjective health constructs, and was used to increase the trustworthiness of the results on wellness perception and psychological symptoms.

Respondents were asked to rate their answers on a rating scale from one to three (never to always).

HBSC Symptom Check-list (SCL) (selected items) (study 2). This scale comprises eight items and two dimensions (somatic and psychological symptoms), and has been validated in a number of studies (Haugland, Wold, Stevenson, Aaroe, & Woynarowska, 2001; Hetland, Torsheim, & Aaro, 2002). It asks adolescents how often in the last six months they have experienced 1) headache, 2) stomachache, 3) backache, 4) felling low, 5) difficulty getting into sleeping, 6) irritability, 7) dizziness and, 8) nervousness; and respondents additionally rate their answers on a rating scale from one to five (about every day to rarely/never) Higher values indicate higher psychosomatic health and the report of less symptom's complaints. In study 2 only the items 4), 6) and 8) were used and this complet scale was used and will be described with more detail in the methodology of Research phase III.

Socio-Contextual Level

- ***Family (empirical study 3):***

Satisfaction with the Family Environment. This outcome was measured with a Cantril's Self-anchoring Ladder (Cantril, 1965), a single item measure, where the adolescents rated their current satisfaction with family environment. Specifically, they were asked to indicate on a 10 steps ladder where they were at that time (0 was the worst possible family environment; 10 correspond to the best possible family environment). This measure has been validated and used in several studies with adolescents (Holstein et al., 2009).

- ***School/Peers Relationships (empirical study 3):***

Pressure with Schoolwork. This outcome was measured with a single item measure, where the adolescents were asked how pressured they felt by the schoolwork they had to do. This measure may affect student's learning and also influence a wide range of non-academic outcomes such as health, health behaviour and well-being. It has been validated and used in several studies with adolescents (Huebner, Suldo, Smith, & McKnight, 2004; Simetin et al., 2011; Torsheim & Wold, 2001). Respondents were asked to rate their answers on a rating scale from one to four (none to a lot).

Perceived School Performance. This outcome was measured with a single item measure, where young people were asked about what, in their opinion, their class teacher(s) think(s) about their school performance compared to their classmates. This measure is a consistent

and strong predictor of health and well-being (Suldo, Riley, & Shaffer, 2006) and has been validated and used in several studies with adolescents (Sulder, & Huebner, 2006; Suldo, Riley & Shaffer, 2006; Véronneau, & Dishion, 2011). Respondents were asked to rate their answers on a rating scale from one to four (very good to below average).

- ***Risk Behaviours (empirical study 4):***

  "Drunkness". This outcome was measured with a single item measure, where young people were asked whether in the last 30 days they had ever had so much alcohol that they were "really drunk". Drunkenness is associated with adverse psychological, social and physical health and its use commonly occurs with other risk behaviours. This measure has been validated and used in several studies with adolescents (Crews & Hodge, 2007; Windle, 2003). Respondents were asked to rate their answers on a rating scale from one to seven (never to more than 40 times).

  "Physical fight". This outcome was measured with a single item measure, where young people were asked how many times during the last 12 months they had been involved in a physical fight. Physical fight is associated with substance use and this measure has been validated and used in several studies with adolescents (Molcho, Harel & Lash, 2004; Sousa, Correia, Ramos, Fraga & Barros, 2010). Respondents were asked to rate their answers on a rating scale from one to four (none to 4 times or more).

  "Self-harm". This outcome was measured with a single item measure, where young people were asked how many times during the last 12 months they had been hurting themselves on purpose. This measure was included on the HBSC/WHO survey of 2014 after being pilot-tested and revised by a panel of experts from the *Aventura Social* research team (Matos & Equipa Aventura Social, 2000-2014), and it was used to increase the trustworthiness of the results on risk behaviour. Respondents were asked to rate their answers on a rating scale from one to 5 (never to 4 times or more).

  "Sadness" (assessed by the Item "feeling so sad, that it seems that I can't take it"). This measure was included in the HBSC/WHO survey of 2010 after being pilot-tested and revised by a panel of experts from the *Aventura Social* research team (Matos, Gonçalves, Gaspar, & Equipa do Projecto Aventura Social, 2005). It was based on the self-reported Symptom's Check-List and in subjective health constructs, and was used to increase the trustworthiness

of the results on wellness perception and psychological symptoms. Respondents were asked to rate their answers on a rating scale from one to three (never to always).

Table V-2. Measures and coding of variables (Research Phase I)

Measures		
Socio-Demographic and Clinical Variables	**Coding**	**Article**
Gender	1=Boy; 2= Girl	1-4
Age (years old)	Min=11; Max=16	1-4
School Grade	1=6th grade; 2=8th grade; 3=10th grade	1-4
Nationality	1=Portuguese; 2=Angolan, Capeverdian, Guinean, Mozambican, S. Tomense; 3=Brazilian; 4=Ucranian, Romanian, Moldavian, Russian; 5=Other	1-4
Family Affluence Scale-FAS		1-4
• "Does family have car/van/other mean of transport?"	1=No; 2=Yes, one; 3=Yes, two or more	
• "How many computers do you have at home?"	1=None; 2=One; 3=Two; 4=More than two	
• "Spending holidays with family in the last 12 months"	1=None; 2=One; 3=Two; 4=More than two	
• "Do you have a bedroom only for yourself?"	1=No; 2=Yes	
Chronic Condition Optional Package Items (HBSC/WHO)		
"Having/not having a long term disease or health problem that has been diagnosed by a doctor" (Having/not having a chronic condition – CC)	1=No; 2=Yes	1-4
"Feeling that the disease affects/does not affect participation and regular attendance in school" (PSCH)	1=No; 2=Yes	1-4
Psychosocial Variables		
Perception of Wellness ("Feeling so sad that it seems that I can't take it")	1=Never or rarely never happens; 2=It happens sometimes; 3=I'm like that almost always	1, 2
Life Satisfaction	0=Worst life possible; 10=Best life possible	1
Symptoms Check-List (SCL-HBSC) (selected items):	8 items, on a 5-point Likert-type scale; 1=worst health; 5=best health	2
"In the last 6 months, with what frequency did you feel": only the items sad/depressed; irritated/bad humour; nervous, fearfull were used.	1=About every day; 2=More than once a week; 3=About every week; 4=About every month; 5=Rarely or never	
Satisfaction with family life	0=Very bad relationship; 10 =Very good relationship	3
"Feeling pressure with homework"	1=None; 2=A few; 3=Some; 4= A lot	3
"Perception of school competence"	1=Very good; 2=Good; 3=Average; 4=Below average	3
Drunkenness ("In the last 30th days, have you ever had so much alcohol that you were really drunk?")	1=Never; 2=1-2 times; 3=3-5 times; 4= 6-9 times; 5=10-19 times; 6=20-39 times; 7=more than 40 times	4
Physical fight ("During the past 12 months, how many times were you in a physical fight?")	1=None; 2=1 time; 3=2 times; 4= 3 times; 5=4 times or more	4
Self-harm ("During the last 12 months, have you ever hurt yourself on purpose?")	1=Never; 2=1 time; 3=2 times; 4= 3 times; 5=4 times or more	4

3.6. Statistical Analysis

Questionnaire' data were scanned, translated and interpreted by the program-Eyes & Hands-Forms, version 5. All data analysis was completed using SPSS version 19.0 for Windows and the level of significance was set at $p<0.05$. The quantitative analyses included various methods presented in **Table V-3**.

Table V-3. Methods used in quantitative statistical analysis (Research Phase I)

Method	Used to
Descriptive analysis	Characterize nominal variables with frequency and percentage for each category, whereas continuous ones by mean, standard deviation and minimum/maximum values.
Chi-square tests	Assess statistical significance of the association between nominal variables.
Independent sample t-test and analysis of variance (ANOVA)	Compare means of continuous variables between independent groups.
Linear regression and multiple linear regression models	Estimate the prediction strength between explanatory variables, and a continuous dependent variable.
Cluster Analysis	Identify structures within the data and assemble adolescents in groups, by means of a K-cluster method.

Concerning covariate variables, the *Family Affluence Scale* was used as a control, in order to avoid a confounding impact of socioeconomic status in the data analysis. This scale was used as a proxy for socioeconomic status, and, it is composed by four items, assessing self-reported material affluence (such as having a car or computer, spending family holidays during the last year and having an independent bedroom) (Currie et al., 2012). According to the summed score of the items, the response categories are low, medium or high socioeconomic status. This scale has been validated and extensively used in studies with adolescents (Currie et al., 2008).

4. Methods: Research Phase III - Clinical Context

4.1. Study Design

This cross-sectional study was conducted in the Outpatient Paediatric Consultation, directed by Professor Dr. Helena Fonseca, which is comprised in the Paediatric Department of *Hospital de Santa Maria*, directed by Professor Maria do Céu Machado from the Medicine

Faculty of University of Lisbon. This department is integrated in the *Centro Hospitalar de Lisboa Norte* (CHLN), which, in combination with the Faculty of Medicine of Lisbon (FMUL) and the Institute of Molecular Medicine (IMM), constitutes the Academic Center of Medicine of Lisbon (CAML) created in 2010. This department provides healthcare to children and adolescents aged from 0 to 18 years old. The Paediatric Department and the Paediatric University Clinic developed their strategy through the commitment to improve the health of patients and the general population, providing health care services, education and research. Health care services are based in a comprehensive medicine perspective, in partnership with families, parents and adolescents, and adopting a transdisciplinary framework, in close connection with the chronic disease's administrator and the transition to adult care services (Machado, 2012). Moreover, it is in line with the Charter for the Hospitalized Child (ACS, 2009; IAC, 1996).

The four last empirical articles of this thesis used data from a clinical population of adolescents with chronic diseases, collected in the above described outpatient department (empirical studies 6-9).

4.2. Ethics

The present research project was conducted in agreement with the APA ethical principles regarding research with human participants (APA, 2010), the World Medical Association Declaration of Helsinki's guidelines (WMA, 2008) and the Order of Portuguese Psychologists (OPP, 2011). These associations have encouraged the investigation with human participants, aiming to understand the causes of diseases, its evolution and effects, and to improve diagnosis and effective interventions. Nonetheless, it is noted that the rights, dignity and the best interests of the subjects must be preserved, highlighting the following ethical principles: 1) Beneficence and Non-Maleficence; 2) Respect of People's Rights and Dignity; 3) Integrity and Social Responsibility; and, 4) Competence.

In addition, a specific ethical approval for this study was obtained from The Ethics Committee for Health from the *Centro Hospitalar Lisboa Norte* (CHLN - EPE), the institution's ethical committees (Compliance with Ethical Standards: Reference PCA-12 Nov.2012-0785), before the data collection. In agreement with the previously described ethical concerns, detailed information about the study aims and procedures was provided to all participants and those who met the inclusion criteria were invited to participate. The participation was voluntary and the

agreement and informed consent required by the ethical committee was obtained, both from parents, and adolescents older than 14 years old. These documents can be consulted in the Part IV-Annexes, Chapter XV.

4.3. Participants

This study included 135 adolescents with a diagnosed chronic disease: diabetes *mellitus*, allergic diseases or neurologic diseases, mainly boys (51.9%), with a mean age of 14±1.5 years old and attending the paediatric outpatient department of a public central hospital. These group of diseases were chosen based on the literature (Barros, 2009; Yeo & Sawyer, 2005), the national frequencies previously identified in HBSC/WHO (Matos et al., 2015) and the availability of access to these adolescents in the clinical context. No disease specific characteristics or associated comorbidities were in focus of this research phase. Most of these adolescents had Portuguese nationality (97.8%), lived in Lisbon (84.4%) and attended the 7-9th school grades (53.3%). They also had 7.5±4.7 years of median time of diagnosis, generally did not felt affected in school or social participation (82.2% and 86.7%, respectively), did not use special equipment due to the disease (61.5%), but mostly took disease-related medication (34.8%).

4.4. Procedure and Instrument

Prior to data collection and in order to prevent possible difficulties in the self-report questionnaire, a pre-test was performed in schools with a group of students of the same ages (but without chronic conditions), and subsequently an evaluation by a group of experts within the area and from *Aventura Social* research team was also conducted.

Using a convenience sampling technique, adolescents and their parents were selected and then approached directly by their health professionals (physicians and/or nurses), who helped to identify the following applied criteria for inclusion: 1) diagnosis of chronic disease, which was established by a physician and also ascertained in the questionnaire; 2) ages including both groups of young teens (12-14 years old) and teenagers (15-17 years old); and 3) to have the cognitive skills necessary to fill out the questionnaire autonomously.

Data were collected (whenever possible in an individual medical office) using a self-reported questionnaire either after or before the medical appointment, according to the most

convenient moment for all (adolescent, parents and health professional's appointments). Research assistance was available to provide support whenever necessary. Adolescents completed the questionnaire themselves, in accordance with literature that has been gradually steering away from the practice of seeking opinion through proxy from parents or healthcare providers. Additionally, also relying on the suggested approach to ask adolescents directly about their chronic health conditions, and the impact of such conditions on their lives, since there is evidence that adolescents can provide a better explanation of their experiences (Mazur et al., 2013; Varni et al., 2005; Michaud, et al., 2004).

A self-report questionnaire was used to assess socio-demographic, clinical and psychosocial variables and it can be consulted in the Part IV-Annexes, Chapter XV. The selected variables were used to address HRQoL (generic measure) and psychosocial functioning in adolescents with chronic diseases. Following the WHO suggestions, the adolescent's HRQoL was assessed at the individual level, including self-reports, and using a developmentally appropriate and cross-culturally instrument (WHO, 1993). These requirements were also met by the KIDSCREEN Group (Ravens-Sieberer et al., 2001).

Socio-demographic consisted of age, gender, geographic region, nationality and education level (adolescents and parents).

Clinical variables comprised: 1) time since diagnosis; 2) the use of special equipment related to the disease; 3) Self-perceived Pain; 4) the item "Does your long-term illness, disability or medical condition affect your attendance and participation in leisure activities with friends, classmates? No/Yes" (PLTF); 5) medication intake related to the disease; and, 6) the item "Does your long-term illness, disability or medical condition affect your attendance and participation at school? No/Yes" (PSCH). Items 4, 5 and 6 are included in the international study Health Behaviour in School-aged Children (HBSC/WHO) (Matos & Equipa Aventura Social, 2000-2014; Roberts et al., 2009), and items 5 and 6 constitute The Chronic Condition Short Questionnaire (CCSQ) (Mazur et al., 2013), the optional package for Chronic Conditions within HBSC/WHO. These items centered on the disease's consequences (missing school classes, medication) assess the effect of the disease on adolescents' activities and enlighten its psychosocial impact, presenting considerable strengths over a single, open-ended item. In addition, co-existing problems related to disease, such as medication intake, and/or missing school classes are reported as good indicators of severity (Mazur et al., 2013), therefore, these items together can be considered as a proxy for disease severity. In the present thesis and for a

shorten term, these items PSCH and PLTF, will be also referred as school participation and social participation, respectively.

To assess Self-perceived Pain, it was used a combination of the most common Pain's Perception Analogic Scales suggested in the literature (Cohen et al., 2007; Jensen, 2008; von Baeyer & Spagrud, 2007), namely the Visual Analogue Scale (VAS), the Numerical Rating Scale (NRS) (Breivik, Björnsson, & Skovlund, 2000; Hollen et al., 2005), and the Faces Scale of Wong-Baker (Wong & Baker, 1988), which are also in accordance with the recommendation of the Portuguese Health Ministry (DGS, 2010a). Due to the small size of the sample, the adolescents were grouped not by categories of disease's intensity, but according to feeling or not feeling pain.

Psychosocial variables included Psychosomatic Health Complaints (SCL), Resilience - Scale Healthy Kids Resilience Assessment Module (RES), Self-regulation - Scale Adolescent Self-Regulatory Inventory – ASRI (SR), and Social Support - Scale of Satisfaction with Social Support (SSSS).

In this Phase III, first, comparisons by type of chronic diseases were conducted, and afterwards, between adolescents feeling affected/not affected in their participation and regular attendance at school (PSCH) and in leisure time with friends (PLTF).

4.5. Measures

For the purpose of the present dissertation, in this phase III only the selected measures presented in **Table V-4** were included in the four empirical articles within the clinical sample (studies 6-9).

HRQoL (KIDSCREEN Scales) (empirical studies 6-9):

- ***KIDS-52, Child and Adolescent Version (empirical study 8):***

  HRQoL's several dimensions were assessed using the instrument KIDSCREEN-52, a long version of the family of KIDSCREEN measures. It is a self-response questionnaire with 52 items that assesses health issues and chronic illness for ages from 8 to 18 years old. It is composed by ten dimensions describing QoL related with health on a 5-point Likert-type scale. Lower values reflect feelings of unhappiness, dissatisfaction and inadequacy. Higher values show feelings of happiness, perception of adequacy and satisfaction within

adolescent's life contexts (Gaspar & Matos, 2008; Gaspar et al., 2012, 2010b; Ravens-Sieberer et al., 2001, 2005, 2008b). In the Portuguese translation and validation of the instrument, the number of items and the coefficient of internal consistency (Cronbach's alpha) for the ten dimensions was: 1) PHY-Physical Well-being, 5 items, α=.77; 2) PBW-Psychological Well-being, 6 items, α=.84; 3) EMO-Mood and Emotions, 7 items, α=.86; 4) SEL-Self-perception, 5 items, α=.60; 5) AUT-Autonomy, 5 items, α=.81; 6) PAR-Parent Relation & Home Life, 6 items, α=.84; 7) FIN-Financial Resources, 3 items), α=.88; 8) SOC-Social Support and Peers, 6 items, α=.84; 9) SCH-School Environment, 6 items, α=.84; and 10); BUL-Being Bullied, 3 items, α=.75 (Gaspar & Matos, 2008; Gaspar et al., 2009a; Matos & Equipa Aventura Social, 2006). In the current clinical population of adolescents with chronic diseases, the Cronbach alpha for the 10 dimensions was: 1) PHY-Physical Well-being, α=.84; 2) PBW-Psychological Well-being, α=.89; 3) EMO-Mood and Emotions, α=.90; 4) SEL-Self-perception, α=.70; 5) AUT-Autonomy, α=.88; 6) PAR-Parent Relation & Home Life, α= .88; 7) FIN-Financial Resources, α=.88; 8) SOC-Social Support and Peers, α=.90; 9) SCH-School Environment, α=.86; and 10); BUL-Being Bullied, 3 items, α=.89.

- ***KIDS-10 Index, Child and Adolescent Version (empirical studies 6, 7, 9):***
  HRQoL was assessed using the instrument KIDSCREEN-10 Index, a short version of the KIDSCREEN-52, from which were selected 10 items, consisting on a global score and unidimensional instrument, with a good internal consistency (Cronbach alpha, α=.82) and satisfactory validity. Each item was answered on a 5-point Likert-type response scale (1=Never; 5=Always) and referring to a time limit ("…focus on your last week"), including questions on physical well-being and energy, psychological well-being, autonomy and relationship with parents, peers and social support, and school environment (Erhart et al., 2009; Rajmil et al., 2014; Ravens-Sieberer et al., 2010a; Ravens-Sieberer et al., 2010b). Total score was obtained by summing all the items, and an overall mean score (0-5) or standardized score (0-100) of generic QoL can be computed for the ten items. Lower values reflect feelings of unhappiness, dissatisfaction and inadequacy in different contexts, such as family, peers and school. Higher values show feelings of happiness, perception of adequacy, satisfaction within life contexts and better QoL. For the global scale, the Portuguese version shows good internal consistency and Cronbach's alpha ranged from α=.60 and α=.88, with mean value of α=.80. Moreover, the confirmatory analysis attested the good fit of the one-dimensional model to the Portuguese data, as well as its structural invariance across age

groups, nationality and socioeconomic status (Gaspar & Matos, 2008). In the current clinical sample of adolescents with chronic diseases the Cronbach alpha was α=.83.

This scale is an optional possibility to address subjective health that has assuming an increasingly importance in health indicators, both in national and international studies, such as the HBSC (Currie, 2001; Currie et al., 2012; Matos & Equipa Aventura Social, 2000-2014; Roberts et al., 2009). It has been used in several countries, including Portugal and it is in line with the definitions of QoL/HRQoL from the WHO and the KIDSCREEN European Group (Matos et al., 2012b).

Individual-Psychological Level

- ***Psychosomatic Health (SCL) | HBSC Symptom Check-list (empirical studies 6-9):***

  This scale is a brief screening instrument with 8 items and a non-clinical measure of mental health, developed for the survey HBSC/WHO (King, Wold, Tudor-Smith, & Harel, 1996). Prior studies on the HBSC-SCL suggested a two-factor solution reflecting two dimensions of health (somatic and psychological) (Haugland et al., 2001; Hetland et al., 2002). However all 8 items can be used together to measure a unidimensional latent trait of psychosomatic complaints, and this assumption of unidimensionality seems sufficient to explain the actual response behaviour of the adolescents (Ravens-Sieberer et al., 2008a; Ravens-Sieberer et al., 2009). The unidimensional scale ranges from 8 to 40 and its internal consistency, reliability and validity has been confirmed (Ravens-Sieberer et al., 2008a). The coefficient of internal consistency (Cronbach's alpha) was α=.78, and in the current clinical population of adolescents with chronic diseases the same value was obtained.

  This scale assesses the frequency of occurrence of eight subjective physical and psychological health complaints namely headache, stomach-ache, backache, feeling-low, irritability or bad mood, feeling nervous, sleeping-difficulties and dizziness. Each item is answered on a 5-point Likert-type response scale (1=About every day; 5=Rarely or Never) and referring to a time limit ("…during the last 6 months"), resulting in values between 1 (worst health) and 5 (best health). Higher values indicate higher psychosomatic health, thus less report of symptoms and health complaints. Most of the selected items for this scale were previously used in other measures of adult and adolescent health status (Haugland et al.,

2001) and health complaints. They are important indicators of well-being and tend to occur together placing an enormous burden for children and adolescents (Ottova et al., 2012).

In the present research it was additionally created a variable designed as Symptoms Check-List (Multiple Complaints) (SCL-MC), composed by those adolescents who reported two or more symptoms, more than once a week in the past six months. This procedure was based on the literature that suggests that adolescents with recurrent multiple health complaints are considered to present noticeable subjective health complaints (Ottova et al., 2012).

- ***Resilience (RES) | Healthy Kids Resilience Assessment Module (empirical studies 6-9):***

  To measure resilience, the Healthy Kids Resilience Assessment Module (versão 6.0) (Constantine & Benard, 2001; Constantine, Benard, & Diaz, 1999), of the California Healthy Kids Survey (CHKS) (http://chks.wested.org/) (CHKS, 2000), adapted to Portuguese (Martins, 2005) was used. The CHKS was developed in 1997 under contract from the California Department of Education (CDE) by WestEd's Health and Human Development Program in collaboration with the Duerr Evaluation Resources. An advisory committee consisting of researchers, teachers, prevention and health program practitioners and public agency representatives assisted on its development (Furlong, Ritchey, & O'Brennan, 2009; Hanson & Kim, 2007). CHKS is a easily tailored, comprehensive self–reporteded youth survey, assessing all major areas of health–related risk behaviour and resilience, that emphasizes the promotion of a positive youth development and well–being.

  The Healthy Kids Resilience Assessment Module was designed to measure protective factors among youth in terms of their internal assets and external resources, using 58 items in 3 subscales: A. external resources; B. internal resources; and C. response-set breakers (Constantine, et al., 1999). The subscale A. is composed by the School Environment, Home Environment, Community Environment and Peer Environment, whereas the subscale B. comprises Cooperation/Communication, Empathy, Problem Solving, Self-efficacy, Self-awareness and Goals/Aspirations. Theoretically, external resources (such as support from teacher, involvement in school-based activities) help to suit the adolescent's developmental needs, which, in turn, promote the enrichment of internal assets (e.g., ability to problem solving and empathize with others). Ideally, these internal resources assess protective factors and personal resilience strengths, critical to healthy development (Austin et al., 2013; Benard & Slade, 2009). This assessment module was based on Benard's resilience model, focused

on the primary youth's needs, such as safety, love, belonging, respect, mastery, challenge, power and meaning (Benard, 1991, 1995, 2004; Benard & Slade, 2009).

In the original study, the reliability and validity was confirmed and the coefficient of internal consistency (Cronbach' alpha) was α=.94 for the total scale; α=.82 for the subscale A. (external resources); and α=.81 for the subscale B. (internal resources). The Portuguese version also comprises external and internal resources and a good internal consistency was obtained with a Cronbach alpha of α=.93 for the total scale, α=.90 for the subscale A. (external resources) and α=.84 for subscale B. (internal resources). Responses were answered on a 4-point scale (1=Not all true; 4=Very much true); the scale ranges from 18 to 72, and higher scores indicate higher levels of competences, protection and resilience in facing adversity (Martins, 2005, 2007). Total and individual subscales scores are obtained by the summation of the corresponding items/subscales in the questionnaire and dividing them by the number of items/subscales, respectively. The Healthy Kids Resilience Assessment Module was first an optional module of the broad CHKS survey, but recently, due to changes in prior versions it was included in the Core Module and referred as the Resilience & Youth Development Module (RYDM) (Austin, Bates & Duerr, 2013).

In Research Phase III it was only used the subscale B. (internal resources). This choice was based on the author's suggestions that more than the total score, the partial scores of the subscales allow a specific analysis of potential intervention domains, in order to promote higher resilience skills. In this subscale, Cooperation/Communication, Empathy and Problem Solving are related to the assets of social competence; Self-efficacy and Self-awareness are related to the assets of autonomy and sense of self; Goals/Aspirations are related to the assets of sense of meaning and purpose (Constantine, Benard, & Diaz, 1999). The coefficient of internal consistency (Cronbach's alphas), both in the original study and in the Portuguese version were: for Cooperation/Communication α=.65 *vs.* α=.57, Empathy α=.73; *vs.* α=.62, Problem Solving α=.72; *vs.* α=.76, Self-efficacy α=.70; *vs.* α=.66, Self-awareness α=.55; *vs.* α=.71, and Goals/Aspirations α=.71; *vs.* α=.61, respectively. Generally, the values were quite similar in the original study ranging from α=.55 to α=.73, and in the Portuguese version ranging from α=.57 to α=.76 (Martins, 2005, 2007). In the current clinical population of adolescents due to the small number of individuals on each one of those competences, the total score of the subscale B. (internal resources), with a Cronbach's

alpha of α=.72 was used. The total Portuguese validated instrument has been used in previous studies (Ferreira, Simões, Matos, Ramiro, & Diniz, 2012; Sereno & Simões, 2013; Simões et al., 2010a; Simões, Matos, Ferreira, & Tomé, 2010b), as well as only the subscale B. (internal resources) (Simões et al., 2012; Simões, Matos & Morgan, 2015).

- ***Self-regulation (SR) | Adolescent Self-Regulatory Inventory (empirical studies 6-9):***
  The Adolescent Self-Regulatory Inventory-ASRI (Moilanen, 2007) was used; this is a theoretically-based questionnaire that comprises two temporal aspects of self-regulation (short and long term), in accordance with the idea that adolescents self-regulate for longer periods of time than children, and in agreement with their own long-term goals (Demetriou, 2000). Self-regulation is an important protective factor that may help to prevent adolescents from engaging in risk behaviours (Jessor & Jessor, 1977) and it is *"...the ability to flexibly activate, monitor, inhibit, persevere and/or adapt one's behaviour, attention, emotions and cognitive strategies in response to direction from internal cues, environmental stimuli and feedback from others, in an attempt to attain personally-relevant goals"* (Moilanen, 2007, pp.2). The ASRI's items were also designed to represent the five self-regulatory functions of the hybrid model of self-regulation of Barkley (Barkley, 1997), including monitoring, activating, adapting, persevering, and inhibiting.
  The questionnaire is composed of 36 items (13 for short-term self-regulation; 14 for long-term self-regulation) and respondents rate how true each item was for them, on a 5-point Likert scale, ranging from 1 (not at all true for me) to 5 (really true for me). The scores range from 36 to 180 and higher scores indicate higher levels of self-regulation. Confirmatory factor analyses of the original scale showed satisfactory internal consistency and validity with a Cronbach's alpha of α=.88 for the total scale; α=.75 for the short-term subscale; and α=.80 for the long-term subscale (Moilanen, 2007).
  In the present research the instrument was translated and back translated from the original English version into Portuguese language by the present PhD student and by a certified translator, and afterwards, it was revised by a group of specialized experts within the area and by the *Aventura Social* research team. A pre-test in schools with groups of adolescents with the same ages was also conducted. Some items related to emotional aspects, namely: *"When I'm sad, I can usually start doing something that will make me feel better"* and *"It is hard for me to keep focused on something I find unpleasant or upsetting"*, were previously used in the national study HBSC in 2010 (Matos & Equipa Aventura Social 2000-2014).

Items were reversed and then summed according to the original authors' suggestions (Moilanen, 2007). Regarding the short-term subscale and in the present study, the items 2 and 8 were not reversed (contrary to the original author's suggestions), after discussion and evaluation by a group of experts and within *Aventura Social* research team. In the current clinical population of adolescents with chronic diseases, the coefficient of internal consistency (Cronbach's alpha) was α=.80 for the total scale, α=.66 for the short-term subscale, and α=.77 for the long-term subscale.

More recently yet not on time for the present research, the original instrument ASRI was adapted to the Portuguese context and new items were tested and included, resulting in a questionnaire with 43 items (19 for short-term and 24 for long-term self-regulation). Currently, research is under way in the stability of its structure, validity, and particularly temporal reliability for the Portuguese population (Dias, Castillo, & Moilanen, 2014).

Socio-Contextual Level

- ***Social Support(SSSS) \| Scale of Satisfaction with Social Support) (empirical studies 6-9):*** It was used the instrument Satisfaction with Social Support Scale for Portuguese children and adolescents, a translation and adaptation of the original social support scale (Ribeiro, 1999). The original scale measures satisfaction with social support and it was created for young adults and adult population in situations of illness, as well as chronic and psychological disease. Several health-related and well-being dimensions were considered while building that scale, originally composed by 15 affirmative self-response sentences, in a 5-point Likert scale from "I totally agree" to "I totally disagree". These items were distributed through four dimensions assessing factors related to social support satisfaction: "Satisfaction with Friendship", "Intimacy", "Family Satisfaction", and "Social Activity".

  The Portuguese version measures satisfaction with social support, considering it crucial for health, well-being and QoL of children and adolescents (Gaspar et al., 2009b). The scale addresses two dimensions: Satisfaction with Social Support (SSS) (positive, 6 items), and the Need for Activities connected to Social Support (NASS) (negative, 5 items). Answers are presented in an ordinal 5- point Likert scale, ranging from "1=completely agree" and "5=completely disagree". The 7 items of the SSS dimension are reversed, and total and individual subscales scores are obtained by summing the corresponding items/subscales in

the questionnaire, and dividing it for the number of items/subscales, respectively. Higher scores indicate higher satisfaction with social support (SSS) or higher satisfaction for not feeling the need to have more social support activities (NASS).The coefficient of internal consistency (Cronbach's alpha) was α=.77. In the current clinical population of adolescents with chronic diseases the values were α=.85 for the total scale, α=.73 for the NASS subscale; and α=.87 for the SSS subscale. This instrument has been used in previous studies (Gaspar, et al., 2009a; Gaspar et al., 2012).

Table V-4. Measures and coding of variables (Research Phase III)

Measures		
Socio-Demographic and Clinical Variables	**Coding**	**Article**
Gender	1=Boy; 2= Girl	6-9
Age (years old)	Min=11; Max=16	6-9
Educational Level (adolescents)	1=Basic 2nd Level (5-6th Grades), 2= Basic 3rd Level (7-9th Grades); 3= Secondary Level (10t-12th Grades)	6-9
Nationality	1=Portuguese; 2=Others	6-9
Educational Level of Father and Mother	1= Basic 1st Level (1st -9th Grades); 2=Secondary Level (10-12th Grades); 3= Superior (or more) Level (University, Post-Graduate)	6-9
Chronic Condition diagnosis	1=Diabetes; 2=Allergic Diseases; 3=Neurological Diseases	6-9
Time since diagnosis (years)	Min=0; Max=16	6-9
"Do you take medication for your disease"	1=No; 2=Yes	6-9
"Do you use any special equipment for your disease"	1=No; 2=Yes	6-9
Self-perceived Pain	0=No; 1=Yes	9
Chronic Condition Optional Package Items (HBSC/WHO)		
"Having/not having a long term disease or health problem that has been diagnosed by a doctor" (Having/not having a chronic condition – CC)	1=No; 2=Yes	6-9
"Feeling that the disease affects/does not affect participation and regular attendance in school" (PSCH)	1=No; 2=Yes	7-9
"Does your long-term illness, disability or medical condition affects your attendance and participation in leisure activities with friends, classmates?" (PLTF)	1=No; 2=Yes	7-9
HRQoL		
KIDSCREEN-10 Index	10 items, on a 5-point Likert-type scale	6, 7, 9
KIDSCREEN-52	10 dimensions, 52 items, on a 5-point Likert-type scale	8
Psychosocial Variables		
Symptoms Check List (SCL-HBSC)	8 items, on a 5-point Likert-type scale; 1=worst health; 5=best health	6-9
Healthy Kids Resilience Assessment Module	18 items answered on a 4-point scale	6-9

Adolescent Self-Regulatory Inventory – ASRI	36 items answered on a 5-point Likert scale	6-9
Scale of Satisfaction with Social Support	12 items answered on a 5-point scale	6-9

4.6. Statistical Analysis

The survey data was transferred to an electronic data file in SPSS 22.0 (Statistical Package for Social Sciences). All variables were checked for data inaccuracy by running SPSS frequencies, and afterwards, an analysis on missing values was conducted. To manage missing data an imputation technique was used, *i.e.*, the practice of filling in missing items. This procedure consisted on the substitution for the individual mean of a participant's observed items for each of his/her missing items, relying on the assumption that the items of a specific scale/subscale are highly interrelated (Osborne, 2013). Despite this technique may introduce bias, taking into account the rather small clinical sample its use was considered an advantage, to prevent statistical power loss resulting from diminished sample size and to conduct standard methods and statistical analyses (Schafer & Graham, 2002).

The psychometric analyses of the previous measures were also performed through an analysis of the coefficient of internal consistency (Cronbach's alpha), previously reported in section 4.5. Measures. All statistical analyses were completed using the SPSS 22.0 (Statistical Package for Social Sciences) and the significance level was set at $p<0.05$.

The quantitative statistical analyses included various methods presented in **Table V-5**.

Table V-5. Methods used in quantitative statistical analysis (Research Phase III)

Method	Used to:
Descriptive analysis	Characterize nominal variables with frequency and percentage for each category, whereas continuous ones by mean, standard deviation and minimum/maximum values.
Principal Components Factor Analysis	Explore the factor structure of composite scales.
Chi-square tests	Assess statistical significance of the association between nominal variables.
Independent sample t-test and analysis of variance (ANOVA)	Compare means of continuous variables between independent groups.
Analyses of Covariance (ANCOVA)	Include variables that are continuous and may have an influence on outcomes, but are not part of the main experimentation.
Linear regression and multiple linear regression models	Estimate the prediction strength between explanatory variables, and a continuous dependent variable.
Logistic regression models	Assess the extent to which independent variables were associated the categories of a dichotomous dependent variable. Adjusted and unadjusted odds ratio (OR) with 95% confidence intervals (CIs) were calculated.

Age, gender, educational level of parents (socioeconomic status's proxy) and PSCH/PLTF (disease severity's proxy) were used as covariate variables, in order to avoid a confounding impact in the data analysis. In addition, categorical variables were transformed into *dummy* variables for linear regressions, whenever necessary. All data were tested for normality prior to any analyses using Shapiro-Wilk and Kolmogorov-Smirnov tests, as well as Levene's test for the homogeneity of the variance. In the regression models, assumptions were graphically analysed, through residual's analysis.

To contribute to a deeper understanding of these group of adolescents within their hospital context, and taking into account the literature suggestions regarding the importance of "giving voice to young people" (Fegran et al., 2014), qualitative analyses were further completed using thematic content analysis (Braun, & Clarke, 2006). Such research intended to increase the knowledge on adolescents/parents' satisfaction concerning the health care services. The consequent work is not in the aim of the current discussion of this thesis, but it is included as a supplemental manuscript in the Part IV–Annexes, Chapter XVI.

PART II – SYSTEMATIC REVIEW AND EMPIRICAL STUDIES

Chapter VI

Research Phase I - Empirical Studies 1-4

Empirical Study 1

Individual Factors Related to Chronic Condition in Portuguese Adolescents: Highlights from the HBSC/WHO Study

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Individual factors related to chronic condition in Portuguese adolescents: Highlights from the HBSC/WHO study*

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ABSTRACT

Background: Adolescence includes a period (10 to 19 years) of profound biopsychosocial changes, constituting potentially difficult challenges, which may become more pronounced in the presence of a chronic condition and its limitations. Responses are not homogeneous and can be quite variable, depending on various specific individual factors. Research comparing adolescents with or without chronic illness, or comparing across different conditions, have been contradictory, not confirming a direct relationship between the degree of suffering and the chronic condition.

Objective: To characterize and assess the impact of: 1) having a chronic condition (CC) and 2) how CC affects school participation; and its association with life satisfaction and perception of wellness, controlling for demographic factors: age, gender and family socioeconomic status (SES).

Methods: 5050 Portuguese adolescents with an average age of 14 years, who participated in the Health Behaviour in School-aged Children/WHO (HBSC).

Results: The majority of the adolescents with CC reported that their condition does not affect school participation. Adolescents with CC who indicated that CC affects school participation felt more frequently unwell and presented lower life satisfaction. Being a boy, younger and having high family socio economic status (SES) were identified as predictors of higher life satisfaction; on the other hand, being a girl, older, having lower SES, living with CC and feeling CC affects school participation, are predictors for feeling more frequently unwell.

Conclusions: These adolescents showed an increased vulnerability, presenting internalized symptoms and lower life satisfaction. Furthermore, when there is simultaneous occurrence of living with CC and that CC affects school participation, the impact was even higher. Thus, it is crucial that future interventions should include the identified predictors, combined with "listen to the voice" of adolescents, throughout the adaptation process.

Key Words: adolescent health; chronic condition; health promotion and prevention; quality of life.

INTRODUCTION

Infant mortality rates are rapidly declining, while the prevalence of childhood chronic conditions (CC) arises, bringing up significant hurdles [1]. Chronic condition refers to any extended/irreversible illness, and asthma, congenital heart disease, epilepsy and diabetes, are the most prevalent in adolescence [2]. Living and managing any chronic condition and its limitation during adolescence (the period from 10-19 years old, where profound bio-psycho-social changes occur), constitutes a major challenge for the individual, his/her family and healthcare professionals [3-5].

Advances in medicine made possible to prolong and enhance the lives of children and adolescents with chronic conditions, however, adolescents are still affected in their general development [5] and face numerous challenges, including: more limitations in everyday life participation [6], more difficulties achieving cognitive skills, family/school/peers relationships, health-related behaviors, health perception [7], developmental milestones, and adhering to daily treatments and transitioning to adult care. So, adolescents with a chronic condition can be at higher risk for an healthy emotional and behavioural psychological development [8,9], and can experience more adjustment difficulties [10,11], as well as internalizing symptoms, such as depression [12,13], anxiety and social withdrawal, and externalizing others related to behaviors [14]. These adolescents are therefore doubly disadvantaged and may engage in risky behaviours in a similar rate as healthy peers, and be more vulnerable to adverse health outcomes [15,16].

Research comparing adolescents with and without chronic condition, or comparing across different conditions, have been contradictory, inconclusive, and not confirming a direct relationship between the degree of suffering and the condition [17]. Some studies suggest increased risk in chronic population [18], others, the possibility of successful adaptation [19]. Responses are quite variable and not homogeneous, depending on various specific individual/contextual factors, and also on the type of condition and emerging limitations, being even worse in the presence of both [2]. Also, the prevalence of different health conditions, namely having a greater number of health problems (3/more compared with 2) concurrently is associated with worse quality of life [20], as well as the type of chronic condition. These results are shown, both in Western and Asian populations [20,21].

Moreover, the effects of a chronic condition extend beyond the individual to the entire family system [22] and scholar context, namely through frequent absences, decline of academic performance, poor self-perceptions of academic competence and difficulties to cope with

classroom demands [23]. Growing up with a chronic condition may contribute for worse health related-quality of life and symptoms of anxiety and depression in young adults [24], placing them at higher risk for poor educational, vocational and social outcomes [25].

Nevertheless, the individual perception-related disease and the adaptation to a chronic condition is a dynamic and changeable process, and it can be moderated by child's age, gender, corresponding socio-cognitive developmental level [26], real perception, exposure to cultural/familiar beliefs [27] and construction of concepts of health and illness [28]. Thus, interpretation, comprehension and meanings associated with the impact of chronic condition are strongly affected by culture and socialization process, and influence its integration in the adolescent life's context [27]. Meanings concerning the disease start to consolidate in scholar ages, and, if both chronic condition doesn't affect participation in school/leisure activities, and, family/school are able to provide appropriate support without excessive anxiety, there are good chances for a good adaptation. Having an older age at the disease's onset or longer disease duration, are higher risks for adjustment difficulties [29]. Boys seem to be significantly more likely than girls to display behavioral and adjustment problems [30], and girls show higher levels of anxiety [31], depression (in insulin-dependent diabetes's adolescents) [32], emotional distress (sadness, expressing depressive symptomatology) and suicide ideation [33]. In general population, consistent with previous research, high anxiety/depression in adolescence is associated with poorer health [34], girls report poorer health outcomes and are at great risk for poor self-rated health, low life satisfaction and multiple health complaints [35,36], also showing higher dissatisfaction with their body image, which specifically affects their self-esteem, life satisfaction and mental health [37]. This may be explained by different internalization and externalization patterns, but gender-specific experiences of puberty may also play a role [38]. Thus, gender differences in almost all countries and regions become more pronounced with age and with older girls being systematically worst off [39].

In addition, cross-cultural data also suggests that life satisfaction/better health is associated with financial satisfaction [40], socioeconomic status and education are strongly associated with several chronic conditions [41], influencing, directly and indirectly, health status and self-perceived health [42-44]. In almost all 22 European countries, groups of lower socioeconomic status have shown higher rates of death, poorer health self-assessments [36,45],

prevalence of subjective health problems and lower health [46,47]. Adolescent's self-rated health, reported mental health and quality of life, also decline significantly, especially in low/middle-income families [48,49], and mental and physical childhood health outcomes have persistent effects on lifetime health and socioeconomic status outcomes [50].

Concluding it can be seen that older pupils, girls, students with low socio-economic status, or frequent health complaints reported decreased mental health [51] and health related quality of life [52]. In Portugal, the studies Health Behaviour School-Aged Children – HBSC [53] and Kidscreen [54], have shown the same tendencies reported in literature (poorer health and life satisfaction in girls and older adolescents), pointing out higher vulnerability in this population.

It seems, therefore, relevant to develop the following work with the aim of characterize and assess the impact of: 1) having a chronic condition (CC), and 2) how the chronic condition affects school participation; and its association with life satisfaction [55] and perception of wellness (item "Feeling so sad that it seems that I can't take it") [56], controlling for demographic factors: age, gender and family socioeconomic status (SES) (FAS: Family Affluence Scale) [57]. It is hypothesized that adolescents living with a CC and feeling that CC affects school participation have greater impairment in their life satisfaction and perception of wellness.

METHOD

Participants

The total sample refers to data from the HBSC 2010 study – Portuguese Survey [58] (www.hbsc.org/) and consisted of 5050 Portuguese adolescents (52.3% girls), with a mean age of 14 years old (*SD*=1.85), attending the 6th, 8th and 10th grades, randomly selected from 256 classes and 125 national public schools. The majority of the children and adolescents have Portuguese nationality (94.4%).

Research Design and Questionnaire

A self-administered questionnaire from the Portuguese sample of the HBSC was used. Portugal was included for the first time in 1996, in 1998 as a full partner, and, since then, the study is carried on every 4 years [53]. HBSC is a school-based, self-report questionnaire developed cooperatively between international researchers according to protocol, and used in

collaboration with World Health Organization. It is essentially a descriptive and cross-sectional correlational in nature, that pretend to assess children and adolescents mental and physical health [59].

The aim of the study is to understand health behaviours and well-being among adolescents, within their social context [60]. Especially designed to be appropriate for adolescents, ageing 11-15, this survey consists of items measuring background factors (e.g., socioeconomic status, family structure), individual and social resources (e.g., body image, school environment), health behaviours (e.g., smoking, dieting, sexual behaviour, violence), and health outcomes (e.g., life satisfaction, psychological well-being, and self-reported health). For the purpose of the present work a set of variables were selected that are described in Table 1 (see Measures).

Procedure

The sample data was collected in 139 schools, randomly selected from the official national list of public schools and stratified by region. In each school, the class was the analysis's unity, and classes were randomly selected in order to meet the required number of students for each grade, according to the international research protocol [59]. The HBSC study followed all the rules for research by the Portuguese Ministry of Education and Regional Offices of Education, and it was approved by the scientific committee, national ethics committee and national data protection. All participating schools made available informed parental consent, required by the committee of parents from each school.

Questionnaires were sent to schools and, according to the protocol, teachers administered the questionnaires in the classroom, with voluntary's student participation. Confidentiality was ensured with anonymous response to the questionnaire and restricted access to HBSC research team members, regarding the work on computing and data analysis. The response rate was of 90% regarding schools. No pupil's refusal was identified.

Measures

For the purpose of this study, the group of students with chronic condition was defined by an affirmative answer to the question: "Do you have any long term disease or health problem that has been diagnosed by a doctor?" Then, in a second step it was inquired the extent to which

having a chronic condition affects or not affects school participation. Variables included in the study are described in Table 1.

Insert Table 1

Statistical Analysis

Questionnaire' data were scanned, translated and interpreted by the program-Eyes & Hands-Forms, version 5. Data was entered for statistical analysis, into the database of the Statistical Package for Social Sciences (SPSS), version 19.0 for Windows. Then, descriptive analysis, ANOVA, Qui-square tests and Multiple Linear Regressions were used to determine the relationship, and to examine the strength of the associations between the analysed variables.

RESULTS

The majority of the children and adolescents do not have a chronic condition (CC) (81%; *N*=3763), and the group who has (19%; *N*=884), reports mainly chronic diseases (88.2%), followed by sensorial (5.2%), motor (4,4%) and cognitive/psychological (2.2%) conditions. Teens that indicate to have a chronic health condition mostly report that the condition does not affect their regular participation in school (85.7%; *N*=1180).

ANOVA and Qui-Square tests were used to better understand specific differences or associations, between the study variables and 1) having/not having a chronic condition (CC), and, 2) how that chronic condition affects/not affects participation and regular participation in school, in respect to a set of other dependent variables, controlling for demographic variables: gender, age and familiar socioeconomic status (FAS/SES).

Insert Table 2

"Having/not having a chronic condition" (Table 2) was not significantly associated with gender or age. Data showed a significantly different distribution according to "Feeling so sad that it seems that I can't take it" [$\chi^2(4, N=4554)=24.39, p\leq 0.001$]. Adolescents with chronic condition feel more frequently "like that almost always" (5.2%), compared with adolescents without chronic condition (3.5%).

Insert Table 3

"Having a chronic condition" and feeling that "CC affects/not affects regular participation and regular attendance in school" (Table 3), were not significantly associated with gender or age. However, a significant association was found regarding "Feeling so sad that it seems that I can't take it" [$\chi^2(2, N=1335)=6.80, p\leq 0.05$]: adolescents with a CC, who feel that the condition affects school, feel more frequently "like that almost always" (8.9%),than adolescents who felt that the condition doesn't affect school (4.1%).

ANOVA was used to analyse the differences between adolescents' life satisfaction. There were no significant differences between adolescents having/not having a CC. However, the group who has a CC and feels that CC doesn't affect school participation, has a higher life satisfaction [$F(1,1340; 12.23, p\leq .001)$] ($M$=7.51, SD=1.84). Socioeconomic status (FAS/SES) showed no significant difference regarding having/not having a CC. Nevertheless, the group who has a CC and feels that CC doesn't affect participation in school, has a higher FAS/SES [$F(1,1331; 5.27, p\leq .05)$] ($M$=5.86, SD=1.86).

A set of multiple linear regression models was carried out to estimate the relationship between: 1) adolescents' life satisfaction and 2) adolescent's wellness ("Feeling so sad that it seems that I can't take it"), using as predictors gender, age, socioeconomic status (FAS/SES) and the CC "status": having/not having a chronic condition (Table 4), or feeling that CC affects/not affects participation and regular attendance in school (Table 5).

Chronic condition

Insert Table 4

An adjusted model was achieved for the perception of well-being (life satisfaction) [$F(4)=72.953, p\leq.05$] and the variance explained by the final model was 6.1%. All predictors, except having/not having a CC, were significantly associated with life satisfaction: boys, younger adolescents, and those who have higher FAS/SES tend to perceive their life as more satisfying.

An adjusted model was also achieved for the perception of wellness ("Feeling so sad that it seems that I can't take it") [$F(4)=54.473$, $p\leq.05$] and the variance explained by the final model was 4.6%. All predictors were significantly associated with "Feeling so sad that it seems that I can't take it". Girls, older adolescents, those who have lower FAS/SES and a CC, feel more frequently "... so sad that it seems I can't take it".

Chronic condition affecting participation and regular attendance in school

Insert Table 5

An adjusted model was achieved for life satisfaction [$F(4)=25.275$, $p\leq.05$], and the variance explained by the final model was 7,0%. All predictors, except gender, were significantly associated with life satisfaction. Younger adolescents, those who have higher FAS/SES and feel that CC doesn't affect school participation, also have better perception of life satisfaction.

An adjusted model was also achieved for "Feeling so sad that it seems that I can't take it" [$F(4)=19.752$, $p\leq.05$], and the variance explained by the final model was 5.4%. All predictors, except SES, were significantly associated with "Feeling so sad that it seems that I can't take it". Girls, older adolescents and those who have the perception that CC affects school participation feel more frequently unwell (more frequently report "... so sad that it seems I can't take it").

DISCUSSION

In the present study we sought to establish a relation between: 1) having a chronic condition (CC), and 2) how that condition affects/not affects participation in school; and its association with life satisfaction and perception of wellness, controlling for demographic factors: age, gender and family socioeconomic status (FAS/SES), in a sample of Portuguese adolescents.

A brief overview of main results shows that the majority of adolescents with a CC mainly report that CC does not affect participation and regular participation in school, in contrast to what is suggested in the literature [23,25]. However, for the both groups, living with a CC and

feeling CC affects school participation, present higher rates for feeling more frequently "... so sad that it seems that I can't take it". Adolescents with CC and feeling that it doesn't affect school participation, present higher FAS/SES and life satisfaction. Also adolescents with CC feel more frequently unwell ("... so sad that it seems I can't take it"), and adolescents with CC and feeling that CC affects school participation present the same results. Thus, feeling more frequently unwell and presenting lower life satisfaction are important factors that can compromise psychological health and adjustment. This data supports the hypothesis suggested in this study and evidenced in the literature, proposing that adolescents living with a CC can have increased vulnerability in general development, presenting lower life satisfaction and internalized depressed symptoms [8,10,13,24], being also consistent with previous research concerning Portuguese studies [53,54]. It is also demonstrated that responses to CC can be worse when 2 limitations occur (having CC and feeling it affects school participation) [2]. Therefore, chronic condition can be considered as a predictor for feeling more frequently "... so sad that it seems I can't take it".

This study also supports previous research concerning the idea that the individual perception-related disease and the adaptation to a chronic condition is a dynamic and changeable process, moderated by gender, age, corresponding developmental levels [26,27,28] and socioeconomic status [36,40,41].

Data concerning CC reports that boys, younger adolescents and having higher FAS/SES, are predictors for perceiving life as more satisfying. On the other hand, being a girl, older, having lower SES and a CC, are predictors for feeling more frequently "... so sad that it seems I can't take it". Concerning CC affecting school participation, being younger, having higher SES and feeling that CC doesn't affect school participation, are also predictors for more life satisfaction. By contrast, being a girl, older and feeling that CC affects school participation, are predictors for feeling more frequently unwell (more frequently "...so sad that it seems I can't take it"). Therefore, it is shown that older children [27,39] and girls [32,35,36] can be at higher risk for a more compromised psychological adjustment, and this might be due to different internalization and externalization patterns [37].

Also it is presented that a lower FAS/SES is associated with poorer life satisfaction, psychological health and quality of life, as reported in the literature [45,46,48,49], as well as the results from previous Portuguese studies [53,54].

Thus, in terms of public health and health psychology, health related quality of life needs to be monitored in children and adolescents with and without CC, and with diverse individual, social and cultural differences [61]. It becomes crucial to have better understanding concerning previous important vulnerable predictors, as well as measures to promote health, wellness and disease prevention, resulting in valid information, that hopefully can help to plan more preventive or suitable effective intervention programs [2,4]. However, literature has already gave some evidences (supported in this study), namely that: 1) adaptation responses to chronic condition in adolescents are quite variable and not homogeneous, depending on specific individual/contextual factors; and, 2) being a girl, older, and having a lower FAS/SES repeatedly appear as important predictors for "poor" health and life satisfaction. Therefore, it is now time for this information to become fundamental for planning interventions.

Beyond these "guiding" predictors, interventions should focus on individual and contextual aspects, where distressed areas are identified, as well as risk and protection factors for each child or adolescent. It is also highlighted the importance to promote early interventions, once difficulties increase as children become older and have to deal with "being different" from peers, while, simultaneously, have to fight for autonomy from parents/adults, integrate a social group and rediscovery their body (being even worse if they are girls and have a lower SES). In addition, literature has given some more improving quality of life's variables to include in interventions, such as helping adolescents to better accept the limitations imposed by chronic disease and readjusting life goals [62]. In Portugal, HBSC and Kidscreen studies have been pointing out the need to strength main support structures (family and school), and alerting health and education systems for the global aspects of mental health, scholar and social integration, and prevention of risk behaviors, putting in evidence crucial variables such as family, school and peers, but still, much more needs to be done.

This study has a number of limitations which should be considered when interpreting the results. First, the used variables were developed post hoc from an existing survey. Consequently, some variables only had a small number of items, the only items available in HBSC questionnaire. Second, the findings were entirely based on adolescents' self-reports (even if this is a widely-used procedure in a national survey design), and biases in perception and reporting cannot be ruled out. Finally, the results are cross-sectional (and not longitudinal), and, therefore, it is more difficult to draw conclusions about the direction of causality between

the variables of interest, and, due to the nature of the design, the ideal longitudinal data was not possible.

Notwithstanding these limitations, this is one of the first investigations concerning the impact of living with a chronic condition in adolescents in a nationally wide Portuguese representative sample – HBSC (Portuguese Survey). So, it is expected that this study's results and previous explained predictors for better life satisfaction and wellbeing can give schools, families, health professionals and health institutions important guidelines, while planning interventions focused for adolescents with chronic condition. Compared with their peers, these adolescents seem to need the same guidance and prevention as any other adolescent [5], in order to provide appropriate and effective support during the transition into adulthood [63]. In addition, it is also increasingly fundamental to "give voice" to children and young people with chronic condition, taking into account their specific wishes, desires, needs, knowledge, competences and rights [64], and, moreover, because they are described as competent interpreters of their "world" [65].

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Table VI-1-1. Variables included in the study

Study Variables	**Range**
Gender	1=Boy; 2= Girl
Age (years old)	Min=11; Max=16
Having/not having a long term disease or health problem that has been diagnosed by a doctor (Having/not having a chronic condition – CC);	1=No; 2=Yes
Feeling that the disease affects/does not affect participation and regular attendance in school;	1=No; 2=Yes
"Feeling so sad that it seems that I can't take it" (Matos, Gonçalves, Gaspar & Equipa Projecto Aventura Social, 2005).	1=Never or rarely never happens; 2=It happens sometimes; 3=I'm like that almost always
Life Satisfaction (Cantril, 1965)	0=Worst life possible; 1;2;3;4;5;6;7;8;9;10=Best life possible
Family Affluence Scale-FAS (Boyce et al., 2006) composed by 4 itens, and used to assess familiar socioeconomic status (SES):	
"Does your family have a car, van or other mean of transport?"	1=No; 2=Yes, one; 3=Yes, two or more
"How many computers do you have at home?"	1=None; 2=One; 3=Two; 4=More than two
Spending holidays with family in the last 12 months	1=None; 2=One; 3=Two; 4=More than two
"Do you have a bedroom only for yourself?"	1=No; 2=Yes

Table VI-1-2. Bivariate analysis (χ^2) of study variables and having/not having a chronic condition (CC), and CC affecting/not affecting school participation

		Adolescents						
Background		**Without CC**		**With CC**		**Total**	**χ^2**	**Df**
		N	**%**	**N**	**%**			
Gender	Boy	1797	**47.8**	395	**44.7**	2192	2.709	1
	Girl	1966	**52.2**	489	**55.3**	2455	(p=0.100)	
"Feeling so sad that it seems that I can't take it"	Never or almost never happens	1915	**52.0**	374	**43.0**	2289	24.388*** (p=0.000)	2
	It happens to me sometimes	1641	**44.5**	450	**51.8**	2091		
	I feel like that almost always	129	**3.5**	45	**5.2**	174		
		Doesn't affect school		**Afects school**		**Total**	**χ^2**	**Df**
		N	**%**	N	**%**			
Gender	Boy	566	48.0	99	50.3	665	0.354	1
	Girl	614	52.0	98	49.7	712	(p=0.552)	
"Feeling so sad that it seems that I can't take it"	Never or almost never happens	569	**49.2**	66	**34.4**	635	18.725*** (p=0.000)	2
	It happens to me sometimes	540	**46.7**	109	**56.8**	649		
	I feel like that almost always	48	**4.1**	17	**8.9**	65		

**p≤ .001; **p≤ .01; *p≤ .05

Table VI-1-3. ***Adolescents' life satisfaction and Family Affluence Scale-FAS/SES: comparisons having/not having CC, and feeling that CC affects/does not affect school participation (ANOVA)***

	Adolescents						
	Having CC		**Not having a CC**				
	M	***SD***	***M***	***SD***	***F***	***DF***	***p***
Life Satisfaction	7.34	1.85	7.47	1.82	3.517	1	.061
	Affects school		**Doesn't affect school**				
	M	***SD***	***M***	***SD***	***F***	***DF***	***p***
	6.99	2.15	**7.51**	1.84	12.233***	1	.000
	Having CC		**Not having CC**				
	M	***SD***	***M***	***SD***	***F***	***DF***	***p***
FAS/SES	5.91	1.84	5.88	1.83	0.291	1	.590
	Affects school		**Doesn't affect school**				
	M	***SD***	***M***	***SD***	***F***	***DF***	***p***
	5.53	1.84	**5.86**	1.86	5.277*	1	.022

***p≤.001; **p≤.01; *p≤.05

Table VI-1-4. ***Predicting 1) Adolescents' life satisfaction and 2)"Feeling so sad that it seems that I can't take it", using as predictors gender, age, Family Affluence scale-FAS/SES and having/not having CC (Multiple linear regression models)***

	Included Variables	B	Std. Error	β	t	R^2
Life Satisfaction (1)	Gender ♂ - ♀	-.110	.053	-.030	-2.062*	.061
	Age	-.210	.014	-.212	-14.573***	
	FAS/SES	.114	.015	.114	7.839***	
	Have/Not Have CC	-.114	.068	-.024	-1.674	
"Feeling so sad that it seems that I can't take it" (2)	Gender ♂ - ♀	.191	.017	.167	9.830***	.046
	Age	.031	.005	.101	6.918***	
	FAS/SES	-.015	.005	-.049	-3.323***	
	Have/Not Have CC	.099	.021	.069	4.676***	

Note. B (unstandardized coefficient) and SE (standard error); β: standardized coefficients.
(1) F= 72.953; (2) F= 54.473
***p≤.001; **p≤.01; *p≤.05

Table VI-1-5. ***Predicting 1) Adolescents' life satisfaction and 2) "Feeling so sad that it seems that I can't take it", using as predictors gender, age, Family Affluence scale-FAS/SES and feeling that CC affects/does not affect school participation (Multiple linear regression models)***

	Included Variables	B	Std. Error	β	t	R^2
Life Satisfaction (1)	Gender ♂ - ♀	-.128	.101	-.034	-1.265	.07
	Age	-.213	.028	-.207	-7.702***	
	FAS/SES	.121	.028	.119	4.416***	
	Affects/doesn't affect school	-.452	.146	-.083	-3.103**	
"Feeling so sad that it seems that I can't take it" (2)	Gender ♂ - ♀	.182	.031	.156	5.785***	.054
	Age	.041	.009	.129	4.770***	
	FAS/SES	-.008	.008	-.024	-.894	
	Affects/doesn't affect school	.188	.045	.112	4.158***	

Note. B (unstandardized coefficient) and SE (standard error); β: standardized coefficients.
(1) F= 25.275; (2) F= 19.752
***p≤.001; **p≤.01; *p≤.05

Chapter VI

Research Phase I - Empirical Studies 1-4

Empirical Study 2

Psychological Well-being and Chronic Condition in Portuguese Adolescents

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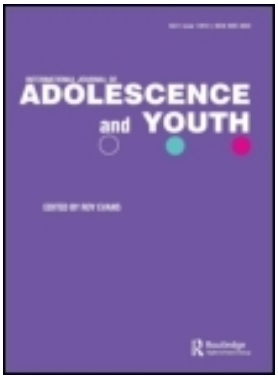

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Psychological well-being and chronic condition in Portuguese adolescents

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ABSTRACT

Objective: To examine the differences in the psychological well-being of Portuguese adolescents' 1) living with a chronic condition (CC); 2) living with a CC and feeling it affects/not affects school participation.

Methods: 5050 Portuguese adolescents, participants of the Health Behaviour in School-aged Children/WHO.

Results: Adolescents without CC often feel rarely or never "sad/depressed", "irritated/bad humour", "nervous", "fearful" or "so sad that it seems I can't take it", compared with their healthy peers. Young people living with CC and feeling that it doesn't affect participation in school, often feel rarely or never "sad/depressed", "fearful" or "so sad that it seems I can't take it", comparing with the ones with CC and feeling it affects school. All of these symptoms were higher in adolescents living with a CC.

Conclusions: Adolescents living with a CC and feeling that it affects participation in school can be at a higher risk for a healthy psychological well-being. Future early interventions based on a "health assets" approach should be implemented.

Keywords: adolescent health; chronic condition; health promotion; health prevention; psychological well-being.

INTRODUCTION

Chronic condition refers to any extended/irreversible illness, being asthma, congenital heart disease, epilepsy and diabetes, the most prevalent in adolescence (Barros, 2009). Living and managing any chronic condition and its limitation during adolescence, where profound bio-psycho-social changes occurs, constitutes a major challenge for young people, his/her family and healthcare professionals (Michaud, Suris & Viner, 2007; Simões, Matos, Ferreira & Tomé, 2010; Suris, Michaud & Viner, 2004).

Actually, the prevalence of childhood chronic conditions (CC) is arising, bringing up significant problems (Delaney & Smith, 2012), while infant mortality rates rapidly decline. Advances in medicine made possible to prolong and enhance the lives of children and adolescents with chronic conditions.

However, their general development is still affected (Suris, Michaud & Viner, 2004) and youth face numerous challenges, namely: more difficulties achieving cognitive skills, family/school/peers relationships, health-related behaviors, health perception (Serrabulho, Matos & Raposo, 2012a); more limitations in everyday life participation (Law et al., 2006), reaching developmental milestones, adhering to daily treatments and transitioning to adult care.

Moreover, the effects of a chronic condition extend beyond the individual to the entire family system (Quittner, Romero, Kimberg, Blackwell & Cruz, 2011) and scholar context, namely through frequent absences, decline of academic performance, poor self-perceptions of academic competence and difficulties to cope with classroom demands (Logan, Simons, Stein & Chastain, 2008). Therefore, adolescents living with a chronic condition can be at higher risk for an healthy emotional and behavioural psychological development (Bernstein, Soren, Stockwell, Rosenthal & Gallagher, 2011; Verhoof, Maurice-Stam, Heymans & Grootenhuis, 2012), and can experience more adjustment difficulties (Geist, 2003; Oeseburg, Jansen, Groothoff, Dijkstra & Reijneveld, 2010), as well as internalizing symptoms, such as depression (Miyazaki, Amaral & Grecca, 2006; Vanhalst et al., 2013), anxiety and social withdrawal, and externalizing others related to behaviors (Lavigne & Faier-Routman, 1992).

Thus, this group is doubly disadvantaged and may be more vulnerable to adverse health outcomes (Saunders, 2011; Scaramuzza et al., 2010). In Portugal, the studies Health Behaviour School-Aged Children-HBSC (Matos & Equipa Aventura Social, 2000, 2002, 2006) and Kidscreen (Gaspar & Matos, 2008), have been also pointing out higher vulnerability in this population. Living with a chronic condition while growing up, may also contribute for worse

health related-quality of life and symptoms of anxiety and depression in young adults (Verhoof, Maurice-Stam, Heymans & Grootenhuis, 2013), placing them at higher risk for poor vocacional/educational and social outcomes (Maslow, Haydon, McRee, Ford & Halpern, 2011).

Nevertheless, the adaptation to a chronic condition and the individual's perception concerning the disease is a dynamic and changeable process, and it can be moderated by child's age, gender, corresponding socio-cognitive developmental level (Holden, Chmielewski, Nelson & Kager, 1997), real perception, exposure to cultural/familiar beliefs (Barros, 2003) and construction of concepts of health and illness (Taylor, Gibson & Franck, 2008). Meanings concerning the disease start to consolidate in scholar ages and having an older age at the disease's onset or longer disease duration are higher risks for adjustment difficulties (Panamonta, Prathipanawatr & Panamonta, 2012). Boys seem to be significantly more likely than girls to display behavioral and adjustment problems (Gortmaker, Walker, Weitzman & Sobol, 1990), and girls show higher levels of anxiety (Matos, Tomé, Borges, Manso, Simões & Ferreira, 2012), depression (La Grecca, Swales, Klemp, Madigan & Skyler, 1995), emotional distress (sadness, expressing depressive symptomatology) and suicide ideation (Suris, Parera & Puig, 1996). In general population, it can be seen that older pupils, girls, students with low socio-economic status, or frequent health complaints reported decreased mental health (Erhart et al., 2009) and health related quality of life (Gaspar, Matos, Ribeiro, Leal & Ferreira, 2009). Also in Portugal, the studies Health Behaviour School-Aged Children – HBSC (Matos & Equipa Aventura Social, 2000, 2002, 2006) and Kidscreen (Gaspar & Matos, 2008), have shown this same tendencies reported in literature.

Despite the data above summarized, research comparing adolescents living with and without chronic condition, or comparing adolescents across different conditions, is still inconclusive, contradictory, and not clear confirming a direct relationship between the chronic condition and degrees of suffering (Combs-Orme, Helfinger & Simpkins, 2002). Certain studies indicate the possibility of successful adaptation (Barros, Matos & Batista-Foguet, 2008), while others suggest increased risk in chronic population (Barlow & Ellard, 2006). There are several heterogeneous responses, depending on various specific individual and contextual factors, plus on the type of condition and emerging limitations, being worst in the presence of both (Barros, 2009). Thus, cumulative risks may have a strong impact and be a threat to adolescent well-being, specifically for psychological symptoms (Simões, Matos, Lebre, & Antunes, 2014). In

addition, having a greater number of health problems (3/more, compared with 2), as well as the type of chronic condition, are concurrently associated with poorer quality of life (Lee et al., 2013). Both in Western and Asian populations there is evidence of such results (Lee et al., 2013; Sawyer et al., 2002).

Consequently, in the present paper it is important to explore the links between adolescents' psychological well-being and 1) living with a chronic condition (CC); and 2) living with a CC and feeling it affects/not affects school participation. Based on the literature it is expected that adolescents with chronic conditions report higher vulnerability in psychological well-being.

METHODS

Participants

The participants include young people from the HBSC 2010 study-Portuguese Survey [58] (www.hbsc.org/) and consisted of 5050 Portuguese adolescents (52.3% girls), randomly selected from 139 national public schools, having a mean age of 14 years old (*SD*=1.85) and attending the 6th, 8th and 10th grades. The majority of the children and adolescents have Portuguese nationality (94.4%).

Research Design and Questionnaire

A school-based self-administered questionnaire from the Portuguese sample of the HBSC was used. Portugal was included for the first time in this study in 1996 and in 1998 was already a full partner. Since then, the study has been realized every 4 years (Matos & Equipa Aventura Social, 2000, 2002, 2006).

The HBSC questionnaire is developed cooperatively between international researchers according to the protocol, and used in collaboration with World Health Organization, and intends to assess children and adolescents mental and physical health (Currie, Samdal, Boyce & Smith, 2001). It is essentially a descriptive and cross-sectional correlation in nature, aiming to understand health behaviours and well-being among adolescents, within their social context (Roberts et al., 2007). Particularly designed to be appropriate for adolescents, ageing 11-15, this survey consists of items measuring background factors (e.g., socioeconomic status, family structure), individual and social resources (e.g., body image, school environment), health behaviours (e.g., smoking, dieting, sexual behaviour, violence), and health outcomes (e.g., life

satisfaction, psychological well-being, and self-reported health). For the purpose of the present work, a set of variables were selected and are described in Table 1 (see Measures).

Procedure

The sample data was collected in 139 schools, randomly selected from the official national list of public schools and stratified by region. The class was the analysis's unity in each school, and classes were randomly selected in order to meet the required number of students for each grade, according to the international research protocol (Currie, Samdal, Boyce & Smith, 2001). The HBSC study follows the principles outlined in the Declaration of Helsinki and all the rules for research by the Portuguese Ministry of Education and Regional Offices of Education, and it was approved by the scientific committee, national ethics committee and national data protection. All participating schools made available informed parental consent, required by the committee of parents from each school.

According to the protocol, questionnaires were sent to schools and teachers conducted their administration in the classroom, with voluntary's student participation. Confidentiality was ensured with anonymous response to the questionnaire and restricted access to HBSC research team members, regarding the work on computing and data analysis. The response rate was of 90% regarding schools. No pupil's refusal was identified.

Measures

For the purpose of this study, the group of students with chronic condition was defined by an affirmative answer to the question: "Do you have any long term disease or health problem that has been diagnosed by a doctor?" Then, in a second step it was inquired the extent to which having a chronic condition affects or not affects school participation. The outcome measure was psychological well-being and four indicators of adolescents' psychological well-being were examined using data from the HBSC/WHO symptom checklist scale (King, Wold, Tudor-Smith, & Harel, 1996). Adolescents were asked how often they had experienced those feelings in the last six months (about every day, more than once a week, about every week, about every month or rarely or never). Variables included in the study are described in Table 1.

[Table 1 near here]

Statistical Analyses

Questionnaire' data were scanned, translated and interpreted by the program-Eyes & Hands-Forms, version 5. Data was entered for statistical analysis, into the database of the Statistical Package for Social Sciences (SPSS), version 19.0 for Windows. After descriptive analysis, bivariate analysis and Qui-square tests were used to determine the differences between respondents' psychological well-being and: "having/not having a CC or health problem diagnosed by a doctor", and if "CC affects/not affects participation and regular attendance in school".

RESULTS

Concerning chronic condition, the majority of the children and adolescents do not have a CC (81%; *N*=3763), and the group who has (19%; *N*=884), reports mainly chronic diseases (88.2%), followed by sensorial (5.2%), motor (4,4%) and cognitive/psychological (2.2%) conditions. Young people that indicate to have a chronic health condition mostly report that the condition does not affect their regular participation in school (85.7%; *N*=1180). Qui-Square tests were used to better understand specific differences between the study variables and 1) having/not having a chronic condition (CC), and, 2) living with a CC and feeling it affects/not affects school participation.

Chronic Condition (Table 2)

"Having/not having a chronic condition" and gender, school grade or nationality were not statistically significant.

The results for "having/not having a chronic condition" and "feeling sad/depressed" [χ^2 (4, *N*=4607)=22.51, $p \leq 0.001$], "feeling irritated/bad humour" [χ^2 (4, *N*=4613)=17.57, $p \leq 0.001$], "feeling nervous" [χ^2 (4, *N*=4616)=18.20, $p \leq 0.001$],, "feeling fearful" [χ^2 (4, *N*=4608)=33,29, $p \leq 0.001$], and "feeling so sad that it seems that it can't take it" [χ^2 (4, *N*=4554)=24,39, $p \leq 0.001$] were statistically significant.

The group of adolescents without a chronic condition often feels rarely or never "sad/depressed" (63.3%), "irritated/bad humour" (54.3%), "nervous" (47.1%), "fearful" (77.2%) or "so sad that it seems I can't take it" (52%), comparing with their healthy peers.

Thus, all of these symptoms were higher in adolescents living with a chronic condition, and reported in a greater frequency concerning the last 6 months (about every day, more than once a day and about every week).

[Table 2 near here]

Chronic Condition Affecting Participation and Regular Attendance in School (Table 3)

"Feeling that CC affects/not affects participation and regular attendance in school" and gender, school grade, nationality, "feeling irritated/bad humour" and "feeling nervous" were not statistically significant.

The results for "CC affecting/not affecting school" and "feeling sad/depressed" [χ^2 (4, N=1359)=11.10, $p\leq0.05$], "feeling fearful" [χ^2 (4, N=1362)=30.89, $p\leq0.001$], and "feeling so sad that it seems that it can't take it" [χ^2 (2, N=1349)=18,73, $p\leq0.001$] were statistically significant.

The group of adolescents living with a chronic condition and feeling that CC doesn't affect participation in school, are often feel rarely or never "sad/depressed" (60.1%), "fearful" (74.3%) or "so sad that it seems I can't take it" (49.2%), compared with the ones living with a CC and feeling that it affects school's participation.

Thus, all of these symptoms were higher in adolescents living with a chronic condition and feeling that it affects participation in school, and reported in a greater frequency concerning the last 6 months (about every day, more than once a day and about every week).

[Table 3 near here]

DISCUSSION

In the present study we sought to establish the links between Portuguese adolescents' psychological well-being and 1) living with a chronic condition (CC); 2) living with a CC and feeling it affects/not affects school participation.

A brief overview of main results shows that the majority of adolescents living with a CC mainly report that CC does not affect participation and regular participation in school, in contrast to what is suggested in the literature (Logan, Simons, Stein & Chastain, 2008; Maslow et al., 2011).

Adolescents living with chronic condition feel more frequently “sad/depressed”, “irritated/bad humour”, “nervous”, “fearful” and “so sad that it seems that it can’t take it”, all reported in a greater frequency concerning the last 6 months, comparing with young people without a chronic condition.

Also the adolescents living with a chronic condition and feeling that CC affects their participation in school present similar results, often feeling more “sad/depressed”, “fearful” and “so sad that it seems that it can’t take it” comparing with the young people that don’t feel that CC affects school’s participation.

Therefore, youth living with a chronic condition seem to be at higher risk for psychological well-being. This data supports the suggested hypothesis in this study and reported in the literature, indicating that adolescents living with a chronic condition can have increased vulnerability for an emotional and psychological healthy development (Bersnstein et al., 2011; Verhoof, Maurice-Stam, Heymans & Grootenhuis, 2012), presenting more internalized symptoms, such as depression (Myiazaki, Amaral & La Grecca, 2006; Vanhalst et al., 2012), and anxiety Lavigne & Faier-Routman, 1992), and this can continue as a risk factor for later in adulthood (Verhoof, Maurice-Stam, Heymans & Grootenhuis, 2013).

Moreover, when adolescents have a chronic condition and feel that it affects school’s participation, data continues to show similar results, namely the higher vulnerability for internalized symptoms, such as depression. The higher psychological vulnerability described above is also consistent with previous research reported in Portuguese studies (Gaspar & Matos, 2008; Matos & Equipa Aventura Social, 2000, 2002, 2006; Simões, Matos, Lebre, & Antunes, 2014). In addition, prior studies conducted in the specific area of chronic condition in Portuguese adolescents reinforced that 1) being a girl, being older, having lower socioeconomic status, living with a CC and feeling it affects school participation, are predictors for feeling more frequently unwell (Santos, Matos, Simões, Fonseca & Machado, 2013); and 2) adolescents with CC have more internalizing behaviours when comparing with healthy peers and adolescents reporting that CC affects school participation have more risky behaviours, while those who are not affected present more healthy behaviours (Santos, Ferreira, Simões, Matos, & Machado, 2014).

In terms of public health and health psychology, this issues need to be monitored in children and adolescents with and without CC, and with diverse individual, social and cultural differences (Gaspar, Ribeiro, Matos, Leal, & Ferreira, 2012). To have better understanding

concerning important vulnerable predictors is crucial, as well as measures to promote health, wellness and disease prevention, resulting in information, that hopefully can help to plan more preventive or suitable effective intervention programs (Barros, 2009; Michaus, Suris & Viner, 2007).

Interventions should be implemented as early as possible and focused on individual and contextual aspects, where distressed areas are identified, as well as risk and protection factors for each child or adolescent. Literature has already given some relevant information to include in interventions, such as helping adolescents to better accept the limitations imposed by chronic disease and readjusting life goals (Casier et al., 2011). In Portugal, HBSC and Kidscreen studies have been highlighted the need to strength the main support structures surrounding adolescents, such as family, schools and peer groups. It also recommended that health and education systems should be alert for the global aspects of youth's mental health. Further, WHO concluded that primary prevention is crucial regarding mental health, pointing out that interventions must consider that most of the health inequalities are based on broad key determinants that co-interact. Thus, WHO recommends an approach based on "health assets", which in relation to young people includes not only exploring individual skills such as resilience, but also community level attributes such as supportive social networks, strong intergenerational relationships and so on (Morrow & Mayall, 2007).

Taking into account all the above described, these suggestions become even more important for young people with chronic conditions, compared with their healthy peers, need the same guidance and prevention as any other adolescent (Suris, Michaud & Viner, 2007), in order to provide effective support during the transition into adulthood (Serrabulho, Matos & Raposo, 2012b). A special attention should also be directed to the adolescents with a CC and feeling that it affects school participaton, in order to prevent the impact of cumulative risk factors (Simões, Matos, Lebre, & Antunes, 2014).

Rather than interventions mainly implemented by adults, it is also increasingly fundamental to "give voice" to children and young people with chronic condition. First, because they are described as competent interpreters of their "world" (Sartain, Clarke & Heyman, 2000), and second, because interventions should and must respect adolescents' specific wishes, desires, needs, knowledge, competences and rights (Michaud, Suris & Viner, 2004).

This study has a number of limitations described below, that should be considered when interpreting the results. The used variables were developed post hoc from an existing survey; consequently, some variables only had a small number of items (the only items available in HBSC questionnaire). Findings were entirely based on adolescents' self-reports (even if this is a widely-used procedure in a national survey design), and biases in perception and reporting cannot be ruled out. Finally, the results are cross-sectional (and not longitudinal), and, therefore, due to the nature of the design, the ideal longitudinal data was not possible. Thus, it is more difficult to draw conclusions about the direction of causality between the variables of interest.

Notwithstanding these limitations, this is one of the first investigations concerning the impact of living with a chronic condition in adolescents in a nationally wide Portuguese representative sample-HBSC (Portuguese Survey). Therefore, it is expected that this study can give important suggestions to families, schools and health professionals, while planning interventions for adolescents with chronic conditions that must take into account the promotion of a healthy psychological well-being.

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Table VI-2-1. Variables included in the study

Study Variables	**Range**
Gender	1=Boy; 2= Girl
Age (years old)	Min=11; Max=16
School grade	1=6th grade; 2=8th grade; 3=10th grade
Nationality	1=Portuguese; 2=Angolan, Capeverdian, Guinean, Mozambican, S. Tomense; 3=Brazilian; 4=Ucranian, Romanian, Moldavian, Russian; 5=Other
Having/not having a long term disease or health problem that has been diagnosed by a doctor (Having/not having a chronic condition – CC);	1=No; 2=Yes
Feeling that the disease affects/does not affect participation and regular attendance in school;	1=No; 2=Yes
Psychological well-being had a physical and psychological symptoms evaluated through the question: "In the last 6 months, with what frequency did you feel" (King, Wold, Tudor-Smith, Harel, 1996): - feeling sad/depressed - feeling irritated/bad humour - feeling nervous, - fearfull.	1=About every day; 2=More than once a week; 3=About every week; 4=About every month; 5=Rarely or never
"Feeling so sad that it seems that I can't take it" (Matos, Gonçalves, Gaspar & Equipa Projecto Aventura Social, 2005).	1=Never or rarely never happens; 2=It happens sometimes; 3=I'm like that almost always

Table VI-2-2. Bivariate analysis (χ^2) for having/not having a chronic condition (CC)

Background		Adolescents				Total	χ^2	Df
		Without CC		With CC				
		N	%	N	%			
Gender	Boy	1797	47,8	395	44,7	2192	2,709	1
	Girl	1966	52,2	489	55,3	2455		
School Grade	6th	1128	30,0	241	27,3	1369	3,673	2
	8th	1200	31,9	278	31,4	1478		
	10th	1435	38,1	365	41,3	1800		
Nacionality	Portuguese	3528	94,3	834	95,1	4362	8,397	4
	Ang./Capv./Gui./Moz./S.T.	51	1,4	11	1,3	62		
	Brazilian	44	1,2	16	1,8	60		
	Ucr./Rom./Mold./Russ.	37	1,0	2	0,2	39		
	Other	81	2,2	14	1,6	95		
Symtoms: Feeling sad/depressed	About every day	173	**4,6**	54	**6,2**	227	22,511***	4
	More than once a week	300	8,0	86	9,9	386		
	About every week	257	**6,9**	84	**9,6**	341		
	About every month	639	17,1	166	19,0	805		
	Rarely or Never	2366	**63,3**	482	**55,3**	2848		
Symtoms: Feeling irritated/bad humour	About every day	127	**3,4**	43	**4,9**	170	17,571***	4
	More than once a week	354	**9,5**	102	**11,7**	456		
	About every week	371	9,9	87	10,0	458		
	About every month	855	**22,9**	228	**26,1**	1083		
	Rarely or Never	2032	**54,3**	414	**47,4**	2446		
Symtoms: Feeling nervous	About every day	223	6,0	67	7,6	290	18,196***	4
	More than once a week	397	**10,6**	125	**14,3**	522		
	About every week	437	11,7	101	11,5	538		
	About every month	922	24,7	227	25,9	1149		
	Rarely or Never	1760	**47,1**	357	**40,7**	2117		
Symtoms: Fearfull	About every day	103	**2,8**	41	**4,7**	144	33,294***	4
	More than once a week	148	**4,0**	65	**7,4**	213		
	About every week	136	3,6	39	4,5	175		
	About every month	463	12,4	115	13,2	578		
	Rarely or Never	2885	**77,2**	613	**70,2**	3498		
"Feeling so sad that it seems I can't take it..."	Never or almost never happens	1915	**52,0**	374	**43,0**	2289	24,388***	2
	It happens to me sometimes	1641	**44,5**	450	**51,8**	2091		
	I feel like that almost always	129	**3,5**	45	**5,2**	174		

***p≤.001; **p≤.01; *p≤.05

Table VI-2-3. Bivariate analysis (χ^2) of study variables and chronic condition (CC) affecting/not affecting participation and regular attendance in school

Background		Adolescents				Total	χ^2	Df
		CC Not Affects School		CC Afecting School				
		N	%	N	%			
Gender	Boy	566	48,0	99	50,3	665	0,354	1
	Girl	614	52,0	98	49,7	712		
School Grade	6th	392	33,2	58	29,4	450	1,101	2
	8th	371	31,4	65	33,0	436		
	10th	417	35,3	74	37,6	491		
Nacionality	Portuguese	1089	93,1	182	93,3	1271	2,537	4
	Ang./Capv./Gui./Moz./S.T.	25	2,1	2	1,0	27		
	Brazilian	21	1,8	6	3,1	27		
	Ucr./Rom./Mold./Russ.	7	0,6	1	0,5	8		
	Other	28	2,4	4	2,1	32		
Symtoms: Feeling sad/depressed	About every day	70	**6,0**	21	**11,1**	91	11,104*	4
	More than once a week	92	7,9	22	11,6	114		
	About every week	101	8,6	15	7,9	116		
	About every month	203	17,4	34	17,9	237		
	Rarely or Never	703	**60,1**	98	**51,6**	801		
Symtoms: Fearfull	About every day	48	**4,1**	15	**7,8**	63	30,894***	4
	More than once a week	65	**5,6**	27	**14,0**	92		
	About every week	42	**3,6**	13	**6,7**	55		
	About every month	146	12,5	21	10,9	167		
	Rarely or Never	868	**74,3**	117	**60,6**	985		
"Feeling so sad that it seems I can't take it..."	Never or almost never happens	569	**49,2**	66	**34,4**	635	18,725***	2
	It happens to me sometimes	540	**46,7**	109	**56,8**	649		
	I feel like that almost always	48	**4,1**	17	**8,9**	65		

***p≤.001; **p≤.01; *p≤.05

Chapter VI

Research Phase I – Empirical Studies 1-4

Empirical Study 3

Contextual Factors related to Chronic Condition in Portuguese Adolescents: Highlights from The HBSC/WHO Study

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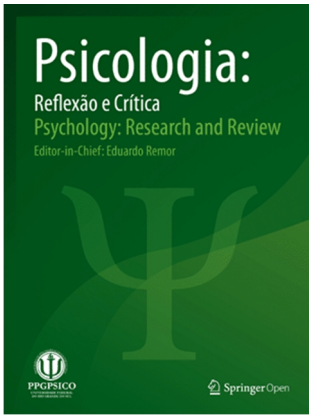

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Contextual factors related to chronic condition in portuguese adolescents: highlights from the HBSC/WHO study

Teresa Santos[1,3*], Margarida Gaspar de Matos[1,2,3], Maria Celeste Simões[1,2] and Maria do Céu Machado[4]

ABSTRACT

Adolescence's changes may become more pronounced when living with a chronic condition (CC). This study aims to examined the differences in satisfaction with family life, perception of school competence and "pressure with homework" of Portuguese adolescents' 1) living with CC; 2) how living with CC affects school participation; taking into account age, gender and family socioeconomic status (SES).

5050 Portuguese adolescents (mean age 14±1.85) of the Health Behaviour in School-aged Children (HBSC/WHO) were included. Results showed increased vulnerability in adolescents living with CC, presenting a lower satisfaction with family life and poor school outcomes. Younger boys, having a higher SES and not having CC are significantly associated with satisfaction with family life. Older girls, having a lower SES and living with CC were associated with more stress related to school work.

Future interventions should include these features combined with 'listening' to adolescents and their needs, allowing their participation in the promotion of personal health.

Key Words: adolescents; chronic condition; satisfaction with family life; school perception; socioeconomic status.

RESUMO

As transformações típicas do período da adolescência podem ainda ser mais pronunciadas quando se vivencia uma situação de doença crónica (DC). Este estudo procura examinar as diferenças na satisfação com a vida familiar, na percepção de competência escolar e na "pressão com os trabalhos de casa" em adolescentes Portugueses que: 1) vivem com DC; 2) vivem com DC e sentem que a mesma afecta a participação na escola; tendo em conta as variáveis de idade, género e estatuto sócio-económico (ESE).

Participaram 5050 jovens (idade média de 14±1.85) do estudo Health Behaviour in School-aged Children (HBSC/WHO). Os resultados demonstram maior vulnerabilidade nos adolescentes com DC (comparando com os que não têm DC), que se traduz por menor satisfação com a vida familiar e piores indicadores escolares. Ser rapaz, mais novo, apresentar ESE mais elevado e não ter uma DC está associado significativamente com melhor satisfação com a vida familiar. Ser rapariga, mais velha, apresentar ESE mais baixo e ter DC está associado com mais stress relacionado com o contexto escolar.

Intervenções futuras devem incluir tais aspectos no planeamento de intervenções, bem como combinar a possibilidade de "dar voz" aos jovens e suas necessidades, permitindo maior participação na promoção da sua saúde individual.

Palavras-chave: adolescentes; doença crónica; satisfação com a vida familiar; percepção escolar; estatuto sócio-económico.

INTRODUCTION

Research that compares adolescents with and without a chronic condition (CC), or different diseases, has been contradictory (Combs-Orme, Helfinger & Simpkins, 2002). Some studies suggest an increased risk in chronic population (Barlow & Ellard, 2006), while others suggest the possibility of a successful adaptation (Barros, Matos & Batista-Foguet, 2008). Responses are not homogeneous and depend on various specific individual and contextual factors, on the type of disease/condition and on emerging limitations (Lee et al., 2013). In spite of medical advances, children and adolescents living with a CC still face numerous challenges and can be at higher risk for a healthy psychological development (Verhoof, Maurice-Stam, Heymans & Grootenhuis, 2012), psychological well-being (Santos, Matos, Simões & Machado, 2015) and more adjustment problems (Oeseburg, Jansen, Groothoff, Dijkstra, & Reijneveld, 2010a).

The effects of a CC extend to the entire family system (Quittner, Romero, Kimberg, Blackwell & Cruz, 2011), which can be a major adaptation facilitator or, on the contrary, a barrier to adjustment (Braconnier & Marcelli, 2000). Parents and parental styles are important in the adaptation process to diseases (Santos, Matos, Simões, Camacho, Tomé, & Moreno, 2013a). However, in those situations, parents seem to be more restrictive, overprotective and authoritarian; still, most families have a good overall functioning and adaptation (Pinquart, 2013). Good communication (Hartos & Power, 1997), a secure attachment relationship, a democratic parenting style and a good social support network are suggested as important protective familiar factors, both in children and adolescents (Moreno, 2004).

In addition, adolescents living with a CC can also experience numerous school difficulties (Harris, Menard-Katcher, Atkins, Furuta & Klinnert, 2013) and academic setbacks (Bethell et al., 2012) including truancy (Boonen & Petry, 2012), poor academic performance, poor self-perception of academic competence, impaired ability to cope with the demands of a classroom (Logan & Simons, 2010), gaps in knowledge/low cognitive development, decreased readiness to learn (Layte & McCrory, 2012) and isolation from peer group (Mazur & Małkowska-Szkutnik, 2010). Young people's perceived school performance and feeling pressured by schoolwork can influence a wide range of non-academic outcomes such as health, health behaviour and well-being (Currie et al., 2012). Missing school, grade retention and school problems are potentially impeding school success variables, placing those adolescents at higher

risk for poor educational, vocational and social outcomes in adulthood (Maslow, Haydon, McRee, Ford & Halpern, 2011).

However, the individual's perception of disease and adaptation to a CC is a dynamic and changeable process, moderated by gender, age, corresponding socio-cognitive developmental level (Holden, Chmielewski, Nelson & Kager, 1997), real perception, exposure to cultural/familiar beliefs and construction of concepts of health/illness (Taylor, Gibson & Franck, 2008). Generally, in Europe, school pressure increases with age and is higher in older girls and younger boys. Perceived good academic achievement tend to decrease with age, and girls are more likely to enjoy school and report higher school performance (Currie et al., 2012). In addition, cross-cultural data suggests an association between better health and financial satisfaction (Oishi, Diener, Lucas & Suh, 1999; Olén, Bihagen, Rasmussen & Ludvigsson, 2012). Thus, high SES adolescents have better classmate support, communication with mother/father and a higher perceived academic achievement (Currie et al., 2012). On the opposite, students living with a CC from lower socio economic status (SES) families tend to miss school classes more frequently (Meng, Babey & Wolstein, 2012) and are at higher risk of perceiving school work and demands as "heavy" (Mazur & Małkowska-Szkutnik, 2010).

In Portugal, the studies Health Behaviour School-Aged Children (HBSC/WHO) (Matos & Equipa Aventura Social, 2000) and Kidscreen (Gaspar & Matos, 2008) have shown similar tendencies, suggesting higher vulnerability population with chronic conditions. These studies also point out the importance of a good communication with parents and peers for adolescents' health (Matos, Dadds & Barrett, 2006; Tomé, Matos, Camacho, Simões & Diniz, 2012) and that school satisfaction is related with higher scores of academic achievement (Simões, Matos, Tomé & Chaínho, 2010). In addition, difficulties in communication are associated with violent behaviors in school and also with both physical and psychological symptoms; while a better parental communication is associated with feeling happier (Matos & Equipa do Projecto Aventura Social, 2000). Further details on Portuguese data concerning chronic diseases and in adolescents, related to individual factors, risk behaviours and psychological well-being have been already published (Santos, Matos, Simões, Fonseca, Machado, 2013b; Santos, Ferreira, Simões, Matos & Machado, 2014; Santos, Matos, Simões & Machado, 2015). It seems, therefore, relevant to study the impact of: 1) living with a chronic condition; and 2) living with a chronic condition that affects school participation, and its association with satisfaction with

family life (Cantril, 1965), "Feeling pressure with homework" and "Perception of school competence". The demographic factors studied within these variables are age, gender and family SES by a proxy (FAS: Family Affluence Scale) (Boyce, Torsheim, Currie & Zambon, 2006).

METHOD

Participants

The present study refers to the Portuguese HBSC 2010 study (Matos et al., 2012b), consisting of 5050 Portuguese adolescents attending the 6th, 8th and 10th grades, randomly selected from 256 classes and 125 national public schools. From the total group of adolescents were included all (N=4647) that answered the question corresponding to having or not having a long term disease or health problem that has been diagnosed by a doctor (missing values excluded). These group has a mean age of 14 years (*SD*=1.85, it is composed by 52.3% girls and 47.7% boys and the majority of the participating children and adolescents have Portuguese nationality (94.4%).

Research Design and Questionnaire

A self-administered questionnaire from the Portuguese study of the Health Behaviour in School-aged Children (HBSC) was used. This study has been carried on every 4 years since 1996 (Matos & Equipa Aventura Social, 2000).

HBSC is a school-based, self-report questionnaire developed cooperatively between international researchers according to protocol, and used in collaboration with the World Health Organization to assess children and adolescents' mental and physical health (Currie, Samdal, Boyce & Smith, 2001; Currie, Gabhainn, Godeau, & The International HBSC Network Coordinating Committee, 2009; Roberts et al., 2009).

The aim of the study is to understand health behaviours and well-being among adolescents, within their social context (Roberts et al., 2007). Especially designed to be appropriate for adolescents aged 11-15, this survey consists of items measuring background factors (e.g., socioeconomic status, family structure), individual and social resources (e.g., body image, school environment), health behaviours (e.g., smoking, dieting, sexual behaviour, violence), and health outcomes (e.g., life satisfaction, psychological well-being, and self-

reported health). For the purpose of the present work a set of variables was selected, described in Table 1).

Measures

For the purpose of this study, the group of students living with a CC was composed by those who gave an affirmative answer to the question: "Do you have any long term disease or health problem that has been diagnosed by a doctor?" In a second step, participants were inquired on the extent to which having chronic disease affects school participation. Other variables included in this study are described in Table 1.

Insert Table 1

Procedure

Data was collected in 139 schools, randomly selected from the official national list of public schools, stratified by region. In each school, according to the international protocol, the class was the analysis's unity and classes were randomly selected in order to meet the required number of students for each grade (Currie et al., 2001). The HBSC study followed all the research rules defined by the Portuguese Ministry of Education and Regional Offices of Education, and was approved by the scientific committee, national ethics committee and national data protection. All participating schools collected informed parental consent.

Questionnaires were sent to schools and, according to the protocol, teachers administered the questionnaires in the classroom with voluntary's student participation. Confidentiality was ensured with anonymous response to the questionnaire and restricted access to HBSC research team members. The response rate was of 92% for schools.

Data Analysis

Data was analysed using the Statistical Package for Social Sciences (SPSS), version 19.0 for Windows. After a descriptive analysis, ANOVA was used to compare life satisfaction and Familly affluence in the different CC conditions, Qui-square tests were used to analyse the distribution of gender, age groups, school competence and pressure with schoolwork in the different CC conditions and finally Multiple Linear Regressions were used to determine the relationship and the strength of the associations between the variables.

RESULTS

The majority of the children and adolescents do not have a CC (81%; *N*=3763), and the group who has (19%; *N*=884) mainly reports chronic diseases (88.2%), followed by sensorial (5.2%), motor (4.4%) and cognitive/psychological (2.2%) conditions. Teens that indicate to have a chronic health condition mostly report that the disease does not affect their participation and regular attendance in school (85.7%; *N*=1180).

Qui-Square tests were used to better understand specific differences or associations between the study variables and 1) having or not a CC, and 2) if that CC affects or not participation and regular attendance in school.

"Having or not a chronic condition" (Table 2) was not significantly associated with gender or "Perception of school competence". Data showed a significantly different distribution according to "Feeling pressure with school homework" [χ^2 (3, *N*=4582)=17.48, $p \leq 0.001$]. Adolescents living with a CC present more frequently (15.5%) "Feel like that a lot" compared with adolescents without chronic condition (11.5%).

"Having a chronic condition (CC) and feeling that it affects or not the participation and regular attendance in school" (table 2) were not significantly associated with gender nor with "Feeling pressure with homework". However, a significant association was found regarding "Perception of school competence" [χ^2 (3, *N*=1366)=10.96, $p \leq 0.05$]. Adolescents with a chronic condition who feel that the disease affects school participation, more frequently (12.8%) "Feel like being a student below average" than adolescents who felt that the disease does not affect school participation (6.4%).

Insert Table 2

ANOVA was used to analyze the differences between adolescents' satisfaction with family life (Table 3) data showed statistical differences between adolescents having or not a CC, and between adolescents feeling that CC affects or not participation in school. The group who does not have a CC has in average higher satisfaction with family life (F(1.4541; 15.47, $p \leq .001$) (M=8.52, SD=1.88), and the same in the group who has a CC but does not feel it affects participation in school (F(1.1335; 19.29, $p \leq .001$) (M=8.41, SD=1.94).

Adolescents' family affluence (FAS) showed no significant difference regarding having or not a CC. Nevertheless, the group who has a CC but feels that the disease does not affect participation in school, has a higher FAS ($F(1.1331; 5.27, p \leq .05)$ (M=5.86, SD=1.86).

Insert Table 3

A set of multiple linear regression models was carried out to estimate the relationship between: 1) adolescents' satisfaction with family life, 2) adolescent's "Feeling pressure with school homework", and 3) adolescent's "Perception of school competence", using as predictors gender, age, socioeconomic status (Family Affluence Scale -FAS) and the chronic disease " status": having or not a CC (Table 4), or, feeling that CC affects or not participation and regular attendance in school (Table 5).

Chronic Condition (Table 4)

An adjusted model was achieved for satisfaction with family life [$F(4)=50.611$, $p \leq .05$], and the variance explained by the final model was of 4.3%. Table 4 shows that although all the four independent variables in the equation are significantly associated to satisfaction with family life, there is a low impact of gender, FAS and having a CC. The higher association is with age (older adolescents feeling worst about family life), and, although with a much lower impact, being a girl and having a CC makes adolescents feel worst about family life. Also in a lower impact, the adolescents who have higher FAS feel more satisfied with family life.

An adjusted model was achieved for "Feeling pressure with school homework" [$F(4)=133.776$, $p \leq .05$], and the variance explained by the final model was of 10.6%. As for this variable, there is a significant but low impact of FAS and having a CC. The higher association is with age (older adolescents feeling more pressure), and with gender (girls reporting more pressure). Although with a much lower impact, not having a CC and reporting a higher FAS makes adolescents feel more "pressure with school homework".

Finally, an adjusted model was achieved for the "Perception of school competence" [$F(4)=76.944$, $p \leq .05$] and the variance explained by the final model was of 6.4%. For this variable there is no significant impact of gender, and there is a significant but low impact of having a CC. The higher association is with age (older adolescents reporting lower school

competence), and with FAS (more affluent adolescents reporting more competence) and, although with a much lower impact, having a CC makes adolescents have a higher perception of school competence.

Insert Table 4

Chronic Condition Affecting Participation and Regular Attendance in School (Table 5)

Table 5 repeat the same models but instead of the variable having/not having a CC, it considers whenever "CC affects/not affects school participation".

An adjusted model was achieved for satisfaction with family life [$F(4)=16.497$, $p\leq.05$], and the variance explained by the final model was of 4.6%. Considering satisfaction with family life, there is no significant impact of gender and a low impact of FAS. The higher association is with age (older adolescents feeling worst with family life) and having a CC that affects school participation makes adolescents feel worst with family life, with a much higher impact than merely considering having or not a CC. With a much lower impact, having a higher FAS makes adolescents feel more satisfaction with family life.

An adjusted model was also achieved for "Feeling pressure with school homework" [$F(4)=45.462$, $p\leq.05$], and the variance explained by the final model was of 12%. As for this variable, there is no significant impact of FAS and of having a CC that affects school participation. The higher association is with age (older adolescents feeling more pressure), and with gender (girls reporting more pressure).

Finally an adjusted model was achieved for "Perception of school competence" [$F(4)=19.620$, $p\leq.05$], and the variance explained by the final model was of 5.3%. For this variable there is no significant impact of gender nor of having a CC that affects school participation. The higher association is with age (older adolescents reporting higher school competence), and with FAS (more affluent adolescents reporting less competence).

Interestingly age seems the worst "risk factor" for (in) satisfaction with family life, pressure with school work and (low) perception of school competence. Focusing on CC, having a CC has a significant but really low impact upon those situations. Interestingly as well is that when considering only having a CC that affects school participation, the impact upon school

pressure and perception of school competence decreases, and the impact upon family life increases.

Insert Table 5

DISCUSSION

A brief overview of main results shows that adolescents living with a CC present higher levels of "pressure with homework" and feel that their school competence is below average. On the other hand, adolescents living without a CC perceive their satisfaction with family life as more satisfying. This data supports the hypothesis evidenced in the literature, proposing that adolescents living with a CC may have increased risk and vulnerability (Barlow & Ellard, 2006; Gaspar & Matos, 2008; Matos & Equipa Aventura Social, 2000; Oeseburg et al., 2010a; Santos et al., 2013b; Santos et al., 2014; Verhoof et al., 2012), mainly in satisfaction with family life (Michaud et al., 2007; Quittner et al., 2011) and school success (Bethel et al., 2012; Layte & McCrory, 2012).

This study also supports previous research that suggests changes can be influenced by gender, age and SES (Currie et al., 2012; Holden et al., 1997; Oishi et al., 1999; Olén et al., 2012; Taylor et al., 2008).

Parents have an important role in the adaptation process to a CC and, concerning school outcomes, parental encouragement can be considered to have a specific positive effect on adolescent health, beyond the effect of school environment and family communication addressed individually (Matos et al., 2006). Thus, family is necessarily an intervention target when pediatric disabling conditions occur in order to help parents deal with children/adolescents' CC and associated changes in the family environment (Russo et al., 2012). Parental interventions should provide key aspects focused on educational, therapeutic and organizational dimensions.

This study has some limitations namely findings were entirely based on adolescents' self-reports (a widely-used procedure in a national survey design) and the results are cross-sectional (and not ideally longitudinal).

Notwithstanding these limitations, this is one of the first investigations concerning the impact of living and attending school in adolescents with CC, using a wide national representative study (HBSC Portuguese study).

Conclusion

Adolescents frequently feel that their lives are ruled by the medical system and so it is increasingly important to include their perspectives in healthcare, highlighting their specific needs, knowledge, competences and rights (Matos, Tomé, Santos, Gaspar & Ramiro, 2013; Michaud, Suris & Viner, 2004; Ottova et al. 2013). It is also important to consider their suggestions to parents, such as learning better parenting styles, having greater confidence in their children, and gradually transferring to them the responsibility for medical treatment (Bregnballe, Schiotz & Lomborg, 2011).

Therefore, a multifaceted approach and prevention of CCs in schools is highlighted and may reduce the costs of special education services, help adolescents to better control the disease and improve a healthy development into adulthood (Logan & Simons, 2010). In addition, when designing and implementing school-based intervention programs, it seems important to promote school assets as important features on school satisfaction and academic achievement for all students and, in particular, for those more vulnerable to achieve success (Simões et al., 2010). Building competences in adolescents with a CC, strengthening connectedness and a better communication within the family, school, peer group and health care professionals will enhance resilience and increase the opportunities to improve health outcomes in this population, creating opportunities to support their school and future professional career (Matos et al., 2012b; Oeseburg, Jansen, Reijneveld, Dijkstra & Groothoff, 2010b).

Competing interests

None of the authors reported any financial interests or potential conflicts of interest.

Author's contributions

TS and MGM conceived the study, participated in its design and coordination, draft and authored the manuscript; CS and MCM participated in the study design, interpretation of the data, and helped to draft manuscript revisions. All authors read and approved the final manuscript.

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Table VI-3-1. Variables included in the study

Study Variables	**Range**
Gender	1=Boy; 2= Girl
Age	Min=11 years old; Max=16 years old
Having or not having a long term disease or health problem that has been diagnosed by a doctor (Having/not having a chronic condition – CC);	1=No; 2=Yes
Feeling that the disease affects or not participation and regular attendance in school;	1=No; 2=Yes
Satisfaction with family life (Cantril, 1965)	0=Very bad relationship; 1;2;3;4;5;6;7;8;9;10=Very good relationship
Family Affluence Scale –FAS (Boyce et al., 2006): composed by 4 items, and used to assess familiar socioeconomic status (SES):	
"Does your family have a car, van or other mean of transport?"	1=No; 2=Yes, one; 3=Yes, two or more
"How many computers do you have at home?"	1=None; 2=One; 3=Two; 4=More than two
Spending holidays with family in the last 12 months	1=None; 2=One; 3=Two; 4=More than two
"Do you have a bedroom only for yourself?"	1=No; 2=Yes
"Feeling pressure with homework"	1=None; 2=A few; 3=Some; 4= A lot
"Perception of school competence"	1=Very good; 2=Good; 3=Average; 4=Below average

Table VI-3-2. Bivariate analysis (χ^2) of study independent variables and 1) having or not a chronic condition (CC), and 2) CC affecting or not participation/regular attendance in school

Adolescents								
Background		**Without CC**		**With CC**		**Total**	**χ^2**	**Df**
		N	**%**	**N**	**%**			
Gender	Boy	1797	47.8	395	44.7	2192	2.709	1
	Girl	1966	52.2	489	55.3	2455	(p=0.100)	
"Perception of school competence	Very good	325	8.7	81	9.2	406	0.346	3
	Good	1415	37.9	331	37.6	1746	(p=0.951)	
	Average	1781	47.7	416	47.3	2197		
	Bellow average	210	5.6	52	5.9	262		
"Feeling pressure with homework"	None	802	**21.6**	148	**17**	950	17.478***	3
	A few	1092	29.4	244	28	1336	(p=0.001)	
	Some	1390	37.4	343	39.4	1733		
	A lot	428	**11.5**	135	**15.5**	563		
		CC Does not Affect School		**CC Affects School**		**Total**	**χ^2**	**Df**
		N	**%**	N	**%**			
Gender	Boy	566	48.0	99	50.3	665	0.354	1
	Girl	614	52.0	98	49.7	712	(p=0.552)	
Perception of school competence	Very good	103	8.8	19	9.7	122	10.964*	3
	Good	426	36.4	61	31.3	487	(p=0.012)	
	Average	567	48.4	90	46.2	657		
	Bellow average	75	**6.4**	25	**12.8**	100		
"Feeling pressure with homework"	None	223	19.2	34	17.5	257	6.068	3
	A few	342	29.5	51	26.3	393	(p=0.108)	
	Some	429	37	68	35.1	497		
	A lot	166	14.3	41	21.1	207		

Table VI-3-3. Adolescents' satisfaction with family life and FAS comparing 1) having or not CC, and 2) feeling that CC affects or not school participation (ANOVA)

	Adolescents						
Satisfaction with family life	**With CC**		**Without CC**				
	M	***SD***	***M***	***SD***	***F***	***Df***	***P***
	8.23	2.06	**8.52**	1.88	15.466***	1	.000
	CC Affects School		**CC does not Affect School**				
	M	***SD***	***M***	***SD***	***F***	***Df***	***P***
	7.71	2.47	**8.41**	1.94	19.293***	1	.000
FAS	**With CC**		**Without CC**				
	M	***SD***	***M***	***SD***	***F***	***Df***	***P***
	5.91	1.84	5.88	1.83	0.291	1	.590
	CC Affects School		**CC does not Affect School**				
	M	***SD***	***M***	***SD***	***F***	***Df***	***P***
	5.53	1.84	**5.86**	1.86	5.277*	1	.022

Indicates significant differences for the following levels:

***p≤.001; **p≤.01; *p≤.05

Table VI-3-4. Predicting 1) adolescents' satisfaction with family life and 2) "feeling pressure with school homework" and "perception of school competence", using as predictors gender, age, FAS and having or not a CC (Multiple Linear Regression Model)

	Included Variables	***B***	***Std. Error***	***β***	***t***	***R²***
Satisfaction with family life (1)	Gender ♂ - ♀	-.169	.057	-.044	-2.982**	.043
	Age	-.185	.015	-.178	-12.097***	
	FAS	.077	.016	.073	4.975***	
	Having or not a CC	-.278	.072	-.057	-3.865***	
"Feeling pressure with school homework" (2)	Gender ♂ - ♀	.288	.027	.152	10.721***	.106
	Age	.145	.007	.283	19.954***	
	FAS	.024	.007	.046	3.254***	
	Having or not a CC	-129	.034	.053	3.778**	
"Perception of school competence (3)	Gender ♂ - ♀	.035	.022	.023	1.600	.064
	Age	-.086	.006	-.210	-14.493***	
	FAS	.053	.006	.128	8.792***	
	Having or not a CC	.072	.028	.037	2.564***	

Note: **B and Std. Error: unstandardized coefficients; β: standardized coefficients.**
(1) F= 50.611
(2) F= 133.776
(3) F= 76.944
***p≤.001; **p≤.01; *p≤.05

Table VI-3-5. Predicting 1) adolescents' satisfaction with family life and 2) "feeling pressure with school homework" and "perception of school competence", using as predictors gender, age, FAS and feeling that CC affects or not school participation (Multiple Linear Regression Model)

	Included Variables	***B***	***Std. Error***	***β***	***t***	***R²***
Satisfaction with family life (1)	Gender ♂ - ♀	-.166	.111	-.040	-1.491	
	Age	-.179	.030	-.161	-5.919***	
	Socioeconomic Status (FAS)	.068	.030	.062	2.276*	.046
	Feeling CC affects/not affects school	-.662	.160	-.113	-4.139***	
"Feeling pressure with school homework" (2)	Gender ♂ - ♀	0.269	0.050	0.139	5.363***	
	Age	0.166	0.014	0.317	12.142***	
	Socioeconomic Status (FAS)	0.017	0.014	0.033	1.255	0,120
	Feeling CC affects or not school	0.090	0.072	0.033	1.254	
"Perception of school competence (3)	Gender ♂ - ♀	-0.064	0.040	-0.042	-1.585	
	Age	0.069	0.011	0.167	6.195***	
	Socioeconomic Status (FAS)	-0.60	0.011	-0.147	-5.563***	.053
	Feeling CC affects or not school	0.037	0.058	0.017	0.631	

Note: **B and Std. Error: unstandardized coefficients; β: standardized coefficients.**
(1) F= 16.497
(2) F= 45,462
(3) F= 19,620
***p≤.001; **p≤.01; *p≤.05

Chapter VI

Research Phase I - Empirical Studies 1-4

Empirical Study 4

Chronic Condition and Risk Behaviours in Portuguese Adolescents

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Chronic Condition and Risk Behaviours in Portuguese Adolescents

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Abstract

Living with a chronic condition (CC) in adolescence has been historically considered protective for risk behaviours. However, research from the last decade suggest that when compared with healthy peers, adolescents living with a chronic condition can engage in risky behaviours in a similar if not higher rate than their counterparts living with out a CC. This study aims to characterize and evaluate the impact of 1) living with a chronic condition (CC), and 2) how the perception of living with a CC affects school participation, and its association with risk/protective behaviours (drunkenness, physical fight, sadness and self-harm). For this purpose 4 groups were identified: adolescents with mostly healthy behaviours, adolescents with mostly risk behaviours, adolescents with mostly risk-internalizing behaviours and adolescents with mostly risk-externalizing behaviours.

A large sample was included in this study, composed by 3494 Portuguese adolescents with an average age of 15 years, who participated in the Portuguese Survey of Health Behaviour in School-aged Children/WHO (HBSC).

Main results show that adolescents living with a CC have more risk-internalizing behaviours when compared to adolescents without CC, who present more healthy behaviors. Furthermore, adolescents that report that having a CC affects school participation show more risky behaviours than those not affected by a CC who present more healthy behaviours. Boys with a CC show more healthy behaviours, and those who feel that the CC affects school participation present more risky behaviours. On the other hand, girls with a CC have more risk-internalizing behaviours and less healthy behaviours

It is important to point out that dolescents living with a CC represent a vulnerable group, and may engage in experimental/risky behaviours as likely as their non CC peers. Thus, potential benefits can arise from reinforcing interventions within protective contexts (family/peers/school setting). Health/education professionals, more than considering risk behaviours as dangerous in themselves, should offer adolescents with a CC an opportunity to reflect on their own decisions. Educational programs would benefit from looking at risk behaviors more from an experimentation perspective, focusing on constructive ways to help adolescents with CC to proceed into adulthood in a more appropriate developmental way.

Keywords: adolescence health, chronic condition, protective contexts, risk behaviours.

1. Introduction

Adolescence comprises a period of profound biopsychosocial changes (Sprinthall & Collins, 1999) with adolescents facing potentially difficult challenges. This period of life may become even more challenged in the presence of a chronic condition and its implications (Michaud, Suris & Viner, 2007; Simões, Matos, Ferreira & Tomé, 2010). Diseases's adaptation process is not homogeneous and can be quite variable depending on various specific individual/contextual factors, and also on the type of condition and emerging limitations, being even worse in the presence of both (Barros, 2009; Lee et al., 2013; Sawyer et al., 2002). Chronic condition relates to any extended and irreversible illness and condition such as asthma, congenital heart disease, epilepsy and diabetes, which are the most prevalent in adolescence (Barros, 2009).

Data indicates that adolescents with disabilities are less exposed to protective factors compared to healthy peers (Blum, Kelly & Ireland, 2001; Svetaz, Ireland & Blum, 2000). Protective factors refer to conditions that improve people's resistance to risk factors and disorders (Coie et al., 1993), which can be, for adolescents with a CC, the condition or the child itself, family, community, or relationships with peers (Nylander, Seidel & Tindberg, 2013).

Adolescent development involves experimental behaviors that can be understood as a normal part of teenage development (Steinberg, 2004). However, sometimes it can lead to risky behaviours that compromise health, quality of life, or life itself (Jessor, 1991). Early onset of sexual activities, unsafe sexual practices, substance use or abuse and violent or antisocial behaviours are all examples of behaviours that might put an adolescent's health at risk. Therefore, risky behaviour can be defined as the participation in activities that may compromise adolescents' physical and mental health, mainly initiated due to developmental characteristics, or influenced by the surrounding environment (i.e. peers and family) (Steinberg, 2004). In fact, a Canadian study showed that, currently, there is a substancial number of young people that consume alcohol, tobacco and drugs and that the simultaneous use of these substances is also very widespread among users. Alcohol was the most prevalent used substance and it was rare to find only tobacco or drugs users (without the simultaneous consumption of alcohol), and, by grade 12, the majority of students were frequent users of alcohol, tobacco or drugs (Leatherdale & Burkhalter, 2012). However, if not early identified, risky behaviour can lead to significant individual, family and social issues (Steinberg, 2004).

In adolescents with chronic conditions, these exploring behaviours part of teenage development have historically assumed a protective role, helping to restrict opportunities that lead to risky behaviours (Frey, Guthrie, Loveland-Cherry, Park & Foster, 1997). Nevertheless, further investigations changed this perspective suggesting that adolescents with chronic conditions are doubly disadvantaged. Adolescents with a CC engage in risky behaviours in a similar if not higher rate, than healthy peers, and are more vulnerable to the adverse health outcomes that result from these behaviours (Blum et al., 2001; Kakleas, Kandyla, Karayianni & Karavanaki, 2009; Saunders, 2011; Sawyer, Drew, Yeo & Britto, 2007; Scaramuzza et al., 2010; Suris & Parera, 2005). Increasing data indicate that adolescents with chronic conditions are encompassed by fewer protective factors (Blum et al., 2001; Svetaz et al., 2000), engage in an equal or even higher amount of risk behaviours than their healthy counterparts (Blum et al., 2001; Sawyer et al., 2007; Suris, Michaud, Akre & Sawyer, 2008; Suris & Parera, 2005) and there is evidence that health risk behaviours tend to cluster together (Suris et al., 2008; Brenner & Collins, 1998; DuRant, Smith, Kreiter & Krowchuk, 1999; Rhee, Yun & Khang, 2007).

Thus, risky behaviour has a negative impact on adolescents's general health and the consequences may be worse for vulnerable individuals, such as adolescents with a chronic condition.

Literature has showed that tobacco consumption is as common in young people with asthma and diabetes as in healthy peers (Precht, Keiding & Madsen, 2003). Alcohol is thought to be the most frequently used substance by adolescents with chronic conditions, with little variation by diagnosis. Both girls and boys with CC seem to report fewer protective factors and more risk behaviours than their healthy peers. Some gender differences were also reported: girls with CC encompassed less individual protective factors, while boys with CC tend to over-report all indivdual risk behaviours, compared to healthy peers (Nylander et al., 2013). On the other hand, comsumption rates for other substances (eg, marijuana) and delinquent behaviour seem to be lower in young people with chronic conditions than in comparison groups (Britto, Garrett, Dugliss et al., 1998). It is important to recall that adolescents's individual variables may predict and influence drinking patterns in adulthood (Windle & Windle, 2012), the specific period where chronic conditions can have a more effective protective role in alcohol consumption (Fat & Shelton, 2012; Liang & Chikritzhs,

2010; Kuntsche et al, 2009). Chronic conditions can also be associated with a slight elevated risk for self-harm (Barnes, Eisenberg & Resnick, 2010). Issues related to sexuality and sexual identity are crucial due to the limitation of contact between peers and adolescents living with a chronic condition which may, as a result, interfere with opportunities for normal sexual experimentation and social development (Suris, Resnick, Cassuto & Blum, 1996).

Still, findings about substance use among adolescents with chronic conditions are inconsistent and unclear (Sawyer et al., 2007; Geist, 2003). Therefore, risk behavioural factors and protective factors require further analysis (Filho & Ferreira-Borges, 2008; Bachman et al, 2008; Nylander et al., 2013).

The effects of a chronic condition extend beyond risky behaviours *per se* and can also compromise a healthy psychological development, cognitive skills, relationship with family/school/peers and health-related behaviours (Michaud et al., 2007). This way, adolescents living with a chronic condition can be at higher risk for a healthy emotional, behavioural and psychological development (Verhoof, Maurice-Stam, Heymans & Grootenhuis, 2012; Bernstein, Sore, Stockwell, Rosenthal & Gallagher, 2011). They can also experience more adjustment problems (Oeseburg, Jansen, Groothoff, Dijkstra & Reijneveld, 2010; Geist, 2003), as well as internalize symptoms such as depression (Vanhalst et al., 2013; Miyazaki, Amaral & Grecca, 2006), anxiety and social withdrawal, and externalize others through specific behaviors (Lavigue & Fier-Routman, 1992). Boys seem to be significantly more likely than girls to display behavioral and adjustment problems (Gortmaker, Walker, Weitzman & Sobol, 1990), and girls show higher levels of anxiety (Matos et al., 2012), depression (La Greca, Swales, Klemp, Madigan & Skyler, 1995), emotional distress (sadness, expressing depressive symptomatology) and suicide ideation (Suris, Parera & Puig, 1996).

There is a large body of evidence linking policy and environmental change to desired behaviour (Ory, Jordan, & Bazzare, 2002) and schools seem to offer an ideal setting where policy's and curricula can influence students (Kuntsche & Jordan, 2006; Mercer et al., 2003) and reduce risk factors for chronic conditions (O'Brien et al., 2010). It is suggested that, providing adolescents adequate information focused on the potential harm of simultaneous use of alcohol, tobacco and drugs may be a useful prevention strategy (Brière, Fallu, Descheneaux & Janosz, 2011; Leatherdale & Burkhalter, 2012). Professionals should also provide stronger protection for these adolescents, to prevent risky behavior (Nylander et al., 2013).

In Portugal, HBSC study (Matos & Equipa Aventura Social, 2010, 2006) and Kidscreen study (Gaspar & Matos, 2008) indicate greater vulnerability of this population and the need for strengthening the main support structures (family and school), warning health and education systems for the global aspects of mental health, scholar and social integration and prevention of risk behaviours (Barros, 2009).

It seems therefore relevant to develop the following study aiming to characterize and evaluate the impact of: 1) having a chronic condition (CC), and 2) how CC affects school participation, in Portuguese adolescents; and its association with health and well-being related risk/protection behaviours, such as drunkenness, physical fight in the last year, sadness and self-harm.

2. Methos

2.1 Participants

Based upon the data from the Portuguese study of 2010 HBSC, the sample of this study is composed by 3494 Portuguese adolescents (53.6% girls and 46.4% boys), with a mean age of 15 years (*SD*=1.29; *Median*=15,17) attending the 8th and 10th grades, randomly selected from 256 classes in 125 Portuguese national public schools.

2.2 Research Design and Questionnaire

A self-administered questionnaire from the Portuguese sample of the Health Behaviour in School-aged Children (HBSC) was used. Portugal was included as a full partner for the first time in 1996 and, since then, the study is carried on every 4 years. HBSC is a cross-sectional design study, a school-based, self-report questionnaire developed cooperatively between international researchers according to protocol. It is used in collaboration with the World Health Organization to assess children and adolescents' mental and physical health (Currie et al., 2012). The aim of the study is to achieve a new and expanded understanding of health, health behaviour and well-being among adolescents within their social context, through the gathering of data that allows national and international comparisons (Roberts et al., 2007). Specially designed to be appropriate for adolescents aged 11-15, this survey consists of 75 items that measure background factors (e.g., socioeconomic status, family structure), individual and social resources (e.g., body image, school environment), health behaviours

(e.g., smoking, dieting, sexual behaviour, violence), and health outcomes (e.g., life satisfaction, psychological well-being, and self-reported health).

2.3. Procedure

The national HBSC study (http://www.hbsc.org/) was approved by a scientific committee and the national ethics committee. The study is essentially descriptive and cross-sectional, correlational in nature.

This sample data was collected in 2010 and the 139 schools were randomly selected from the official national list of public schools and stratified by region. According to the international protocol, in each school, the class was the analysis's unity and classes were randomly selected in order to meet the required number of students for each grade (Currie et al., 2012). The study followed all the research rules defined by the Portuguese Ministry of Education and Regional Offices of Education. All participating schools made available informed parental consent, required by the parent association of each school.

Questionnaires were sent to schools and, according to the protocol, teachers administered the questionnaires in the classroom with voluntary student participation. Confidentiality was ensured through anonymous responses to the questionnaire. Regarding the work on computing and data analysis, there was a restricted access to HBSC research team members. Details about the study procedures can be consulted in the national Portuguese reports (Matos & Equipa Aventura Social, 2006, 2010).

2.4. Measures

The international standard questionnaire consists of three levels of questions which are used to create national survey instruments: core questions that each country is required to include to create the international dataset; optional packages of questions on specific topic areas from which countries can choose from; and country-specific questions related to issues of national importance. Survey questions cover a range of health indicators and health-related behaviours as well as the life circumstances of young people. Questions are subjected to validation studies and piloting at national and international levels (Roberts et al., 2009). For the purpose of this specific study, the questionnaire includes questions about risk/protective behaviours and chronic condition, and the used questions are presented in table 1.

Insert Table 1

2.5 Data Analysis

Questionnaires were scanned and data entry was done using the Program Eyes and Hands forms, version 5. The data was then entered into a database and analysed using the Statistical Package for Social Sciences, version 19.0 for Windows. Descriptive statistics including frequencies, means and standard deviations were performed to give gener descriptions of the data, using the Chi-square ($\chi 2$) tests to analyse differences between having or not a chronic condition. The level r statistical significance was set at $p<.05$. Only significant results were discussed.

The variables about risk behaviours, namely Drunkenness, Physical fight, Sadness and Self-harm were standardized through Z-score, and an analysis through K-cluster was performed, in order to assemble adolescents in groups by means of a K-cluster method.

3. Results

The majority of students in the sample do not have a chronic condition (80.4%) and from those who say they have a chronic condition (n=643), about one-fifth report that the chronic health condition affects their participation and attendance in school (18.7%). Analyzing the differences between gender and age group we can verify there are no differences between groups, in both cases (table 2).

Insert Table 2

Four groups were named according to the adolescent's personal more frequent situation regarding drunkness, physical fights, sadness and self-harm (table 3): adolescents that, in general, present all risk behaviours were named "Adolescents with mostly risk behaviours" (group 1) (N=261, 8.3%); adolescents that only present risk-internalizing behavious such as feeling sad, were named "Adolescents with risk-internalizing behaviours" (group 2) (N=1354, 43%); adolescents that do not present such risk behaviours, were named "Adolescents with mostly healthy behaviours" (group 3) (N=1250, 39.7%); and adolescents that mostly present risk-externalizing behaviours such as excessive drinking, fighting and self

harming were named "Adolescents with risk-externalizing behaviours" (group 4) (N=286, 9.1%). As seen in Table 3, a positive association means that a behavior/situation was found to be significantly more frequent in a specific group, whereas a negative association means that a behavior/situation was found to be significantly less frequent in a specific group (Maroco, 2007).

The results of the chi-square test showed that adolescents with chronic condition have more internalizing behaviours ($\chi2$=24.01(3), $p\leq$.001, 47.6%), while adolescents without chronic condition are more frequently in the cluster with mostly healthy behaviours ($\chi2$=24.01(3), $p\leq$.001, 41.3%). If the chronic condition affects their participation and attendance in school, the adolescents are more frequently in the cluster "mostly risk behaviours" ($\chi2$=20.27(3), $p\leq$.001, 20.3%), while adolescents who refer that chronic condition doesn't affect their school participation and attendance are more frequently in the group with mostly healthy behaviours ($\chi2$=20.27(3), $p\leq$.001, 37.2%).

Insert Table 3

Comparing the same variables, having a chronic condition diagnosed by a doctor and if that chronic condition affects attendance and participation at school, by gender, it's possible to verify that boys with chronic condition are more frequently in the cluster "mostly healthy behaviours" ($\chi2$=17.88(3), $p\leq$.001, 48.9%) while boys without chronic condition are more frequently in the cluster with "mostly risk behaviours" ($\chi2$=17.88(3), $p\leq$.001, 12.7%). In the same way, boys whose attendance and participation in school were affected were more frequently in the cluster with "mostly risk behaviours" ($\chi2$=16.54(3), $p\leq$.001, 26.3%). On the other hand,boys whose participation was not affected were more frequently included in the cluster "mostly healthy behaviours" ($\chi2$=16.54(3), $p\leq$.001, 43.3%). Girls with chronic condition were found more frequently in the cluster "internalizing behaviours" ($\chi2$=8.83(3), $p\leq$.05, 58.2%) and girls without chronic condition more frequently in the cluster "mostly health behaviours" ($\chi2$=8.83(3), $p\leq$.05, 34.8%).If the chronic condition affects attendance and participation in school, no statistical significant differences were found for girls (table 4).

Insert Table 4

4. Discussion

In the present study we sought to establish a relation between: 1) having a chronic condition (CC), and 2) how that condition affects/does not affect participation in school; and its association with health and well-being related risk/protection behaviours, such as drunkenness, physical fight in the last year, sadness and self-harm, in a sample of Portuguese adolescents.

Results showed that adolescents living with a chronic condition have more risk-internalizing behaviours, while adolescents without a chronic condition present more healthy behaviours. Adolescents living with a chronic condition and feeling that the CC affects their participation and attendance in school have more risky behaviours, while adolescents who refer that the chronic condition doesn't affect school have more healthy behaviours. This data supports the hypothesis evidenced in the literature, proposing that adolescents with a chronic condition are doubly disadvantaged and more vulnerable, engaging in risky behaviours in a similar if not higher rate, when compared with healthy peers (Blum et al., 2001; Kakleas et al., 2009; Nylander et al., 2013; Sawyer et al., 2007; Saunders, 2011; Scaramuzza et al.., 2010; Suris & Parera, 2005). It is also demonstrated that responses to disease can be worst when 2 limitations occur (having a CC and feeling it affects school participation) (Lee et al., 2013; Barros, 2009; Sawyer et al., 2002). Comparing the same variables by gender, boys with a chronic condition report more healthy behaviours and boys without a chronic condition report more risky behaviours. Also boys whose attendance and participation in school was affected reported more risky behaviours. Boys whose participation was not affected reported more healthy behaviours. Girls living with a chronic condition present more internalizing behaviours and girls without a chronic condition more healthy behaviours. Also, this data supports the idea that girls have more internalized behaviours (Matos et al., 2012; Suris et al., 1996; La Greca et al., 1995) than boys.

Adolescents explore and experiment different life styles and typical adult behaviours for various reasons, mainly to promote independence from parents and develop an individual identity. Therefore, experimenting with disease management is an example of explorative behavior; it serves developmental needs and, in this way, is not considered the same as risk-taking. However, young people are not truly able to make rational decisions until the maturation of the brain (around the age of 23–25). Therefore, in order to promote a healthier

adolescent development it is crucial to understand protective contexts, such as family, peers and school, and place human free choice as a central topic of discussion. This is where health professionals and educators should offer adolescents an opportunity to think and talk about their choices. More than considering risk behaviour as dangerous in itself, it is important to keep a dialogue with teens and promote education concerning risky behaviour to help them proceed toward adulthood in the safest way possible (Scaramuzza et al., 2010).

Both family and school constitute target groups for interventions that aim at promoting resilience and thus preventing health risk behaviours (Nylander et al., 2013). The school context (peer group) and social environment in which the adolescent is integrated has been identified as the most consistent predictor of substance use in adolescence (Kuntsche & Jordan, 2006; Kuntsche et al, 2009), highlighting the need to explore the behaviours associated with these specific contexts. In addition, motivation and perception of belonging to a culture or group are also other consistent predictors of substance use. Thus, these are crucial factors that require further analysis in order to enhance prevention of behaviours that are harmful to one's health (Filho & Ferreira-Borges, 2008; Bachman, et al, 2008). Schools seem to offer an ideal setting where policies and curricula can influence students (Mercer et al., 2003) and help reduce risk factors for chronic disease, simultaneously (physical activity, dietary behaviour, and tobacco use) (O'Brien et al., 2010). Schools can help reduce risk behaviours in adolescents with chronic conditions, as in healthy adolescents, through the promotion of healthy lifestyles and the prevention of chronic conditions in future adulthood.

Healthcare professionals are also important both in primary and secondary prevention, assuming a relevant role in disseminating knowledge among parents, school staff and significant adults in young people's leisure activities. Therefore, they should aim at strengthening protective factors helping the adolescent in order to ensure resilience and prevent health risk behaviour.

Two limitations must be addressed regarding this study. The first concerns the self-report nature of the surveys: self-reported data depends on selective memory and therefore the findings may be biased. The second limitation has to do with the extent to which the findings can be generalized. Though the number of cases allows it to be a nationwide study, the findings cannot be generalized beyond Portugal because the majority of the sample is Portuguese and there are specific cultural values and beliefs related to the variables being studied.

5. Conclusion

In addition to understanding the whole context in which adolescents are involved, it is important to rethink strategies. As the HBSC is a research and monitoring study, resulting in the construction of a coherent set of indicators that, taken together, provide a valid representation of health and lifestyles of adolescents, it also aims to inform/impact health education policies and national/international programs and interventions for adolescents, in order to promote health and prevent risk behaviours

6. Key-Findings

Portuguese adolescents with a CC can be a vulnerable group and engage in risky behaviours as likely as their non CC peers. Thus, potential benefits can arise from reinforcing interventions in protective contexts, such as family, peers and school.

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Table VI-4-1. Questions about risk behaviours and chronic condition used in the present study

	Items	Responses
Drunkenness	In the last 30th days, have you ever had so much alcohol that you were really drunk?	1. Never 2. 1-2 times 3. 3-5 times 4. 6-9 times 5. 10-19 times 6. 20-39 times 7. More than 40 times
Physical fight	During the past 12 months, how many times were you in a physical fight?	1. None 2. 1 time 3. 2 times 4. 3 times 5. 4 times or more
Sadness	I'm so sad that it seems that I cannot stand it	1. Never or almost never 2. Sometimes 3. Often
Self-harm	During the last 12 months, have you ever hurt yourself on purpose?	1. Never 2. 1 time 3. 2 times 4. 3 times 5. 4 times or more
Chronic condition (CC)	Do you have any long term illness, incapacity, disability or health problem that you have been diagnosed by a doctor?	1. Yes 2. No
Participation in school	This prolonged illness, disability, health problem or disability affects your attendance and participation in school?	1. Yes 2. No

Table VI-4-2. Pupils distribution according to gender/grade and chronic condition

	Gender						**Grade**					
	Boys		**Girls**				**8th**		**10th**			
	N	**%**	**N**	**%**	**χ^2**	**Df**	**N**	**%**	**N**	**%**	**χ^2**	**Df**
Chronic condition (N=3278)					.072	1					.292	1
No	1235	81.7	1400	79.2			1200	81.2	1435	79.7		
Yes	276	18.3	367	20.8			278	18.8	365	20.3		

**p≤ .001; **p≤ .01; *p≤ .05

Table VI-4-3. Final Cluster Centers after a K-cluster analysis using four risk behavior variables ("Drunkenness", "Physical fight", "Sadness" and "Self-harm") using standardized through Z-score

	Mostly Risk Behaviours (Group 1)	**Internalizing Behaviours (Group 2)**	**Mostly Healthy Behaviours (Group 3)**	**Externalizing Behaviours (Group 4)**
Drunkenness	.30	-.10	-.19	1.00
Physical fight	.39	-.30	-.30	2.38
Sadness	.73	.84	-1.00	-.15
Self-harm	3.04	-.24	-.31	-.21

Table VI-4-4. Cluster membership distribution by CC and CC affecting school participation – total and by gender.

	Mostly Risk Behaviours (Group 1)		**Internalizing Behaviours (Group 2)**		**Mostly Healthy Behav (Group 3)**		**Externalizing Behaviours (Group 4)**		**Total**	χ^2	***df***
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**			
Chronic condition (CC)										24.01***	3
Yes	70	**11.6**	288	**47.6**	199	**32.9**	48	7.9	605		
No	184	**7.4**	1046	**41.9**	1031	**41.3**	235	9.4	2496		
CC Affecting school										20.27***	3
Yes	25	**20.3**	57	46.3	26	**21.1**	15	12.2	123		
No	70	**9.4**	327	44.0	277	**37.2**	70	9.4	744		
Chronic Condition by Gender											
Boy										*17.88****	*3*
Yes	69	**6.0**	343	29.8	563	**48.9**	177	15.4	1152		
No	32	**12.7**	82	32.7	98	**39.0**	39	15.5	251		
Girl										*8.83**	*3*
Yes	38	10.7	206	**58.2**	101	**28.5**	9	2.5	354		
No	115	8.6	703	**52.3**	468	**34.8**	58	4.3	1344		
CC Affecting school Participation by Gender											
Boy										*16.54****	*3*
Yes	15	**26.3**	15	26.3	14	**24.6**	13	22.8	57		
No	34	**9.9**	105	30.5	149	**43.3**	56	16.3	344		
Girl										*6.47 (n.s.)*	*3*
Yes	10	15.2	42	63.6	12	**18.2**	2	3.0	66		
No	36	9.0	222	55.5	128	**32.0**	14	3.5	400		

* p< .05; ** p< .01; *** p< .001

In bold – values that correspond to an adjusted residual ≥ │1.9│

Chapter VII

Research Phase II - Scientific Study 5

Scientific Study 5: Systematic Literature Review

(Health-related) Quality of Life and Psychosocial Factors in Adolescents with Chronic Disease: a Systematic Literature Review

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2016, *Health and Quality of Life Outcomes*
(Manuscript submitted for publication).

ABSTRACT

Background: Over the past decades, research on living with chronic disease in youth is increasing, but further research is needed concerning the impact on psychosocial factors in the specific period of adolescence. The present review examines the recent evidence, focusing on the possible association between living with chronic disease in adolescence and the impact on quality of life (QoL), health-related quality of life (HRQoL) and psychosocial functioning.

Methods: Literature review on records identified through PubMed, EBSCO Host and PsycINFO. Only original peer-reviewed research papers, published between 2010 and 2015, non-qualitative research, and reporting on associations between chronic disease in adolescence and QoL/HRQoL and psychosocial factors were considered.

Results: Eighteen papers met the inclusion criteria. The majority of the studies showed a significant higher risk of impairment of QoL/HRQoL and psychosocial functioning. However, contradictory results were found and some studies reported a significant lower risk of impairment, pointing out possible protective factors, and others, no significant differences. Heterogeneity in assessment procedures and substantial difficulties in considering the period of adolescence as a single and independent age group (with specific developmental needs) were also found.

Conclusions: The higher risk of impairment and the heterogeneity observed follow the same direction as previous research, reinforcing the need to work towards consensual procedures, which allow more accurate comparisons among studies. It also brings an additional challenge for researchers/clinicians to rethink what has been done, and to find more effective interventions. Furthermore, it is highly suggested to routinely assess HRQoL and psychosocial factors within an individualized framework, to considerer adolescents as a single/independent group, to emphasize potential protective factors, and, to increase the participation of youth in their own adaptation process, and in health promotion in general. These are possible future directions that could enable multidisciplinary responses to improve HRQoL and psychosocial care in these age group.

Keywords: Adolescents; Chronic Disease; Quality of life; Health-related quality of life; Psychosocial factors; Psychosocial adaptation.

INTRODUCTION

Survival rates of chronic diseases in adolescence have globally increased in the last decades, due to advances in pediatric medicine and life expectancy at birth [1]. However, young people may feel that living with a chronic health condition can impair physical, cognitive, social and emotional dimensions [2,3], as well as general quality of life – QoL [4,5], and health-related quality of life – HRQoL [6,7].

Adaptation responses to a chronic disease are heterogeneous and quite variable, depending on diverse specific individual/contextual factors, and also on the condition and emerging limitations [8-11]. As individual's age, physical influences tend to diminish and psychosocial factors become more important [5,12], combining both psychological and social perspectives [13]. Psychosocial is a term widely used in literature related to health outcomes [14,15], based on the World Health Organization's (WHO) definitions of health [16] and QoL [17,18]. Such constructs, as well as HRQoL [19] are important given their implications for adolescents' well-being, health outcomes, and for a successful everyday life [20]. Additionally, underline a holistic perspective, taking into account that individual and disease life experiences influence psychological, physical, and social well-being [21], and according to the World Health Organization Quality of Life Assessment Group [18]. In clinical and pediatric settings, the psychosocial development and well-being of these adolescents have been increasingly recognized and acknowledged [22-26] as a complement to traditional health indicators, and can be considered as important as medical and dietetic assessments [25]. Thus, drawing attention to the need to access psychosocial variables (such as emotional health and socialization) and the impact of the disease in ordinary activities, reducing the focus on diagnosis categories [27,28] and on disease-related factors [29].

The definition of QoL in children/adolescents may not be directly applicable as in adults, therefore, it implies an ecological perspective [30], including multiple levels of analysis, namely self-perceptions and family perceptions. However, it was often assume that children were unreliable informants of their QoL and research mostly used proxies from mothers [19]. Yet, because children and parents have different views concerning the impact of the disease, efforts were done to involve children and adolescents in decisions about their own treatment and care. The WHO guidelines [17] for the assessment of QoL in these population recommend the use of developmentally appropriate, cross-culturally comparable instruments and generic and specific assessment modules. It also emphasizes the use of self-

reports whenever possible, once cognitive studies confirm that youngsters are able to provide such patient-reported outcomes, reinforcing the idea to ask them directly about their health, health-related needs and feelings [31-36]. In addition, a multiple levels of analysis (self- and proxy-perceptions) [37] and the use of parent-reports as complementary sources of information is also highly recommended in pediatric contexts, due to the parent's responsibility role in clinical decision-making processes [38]. Nevertheless, it is also important to take into account that research also report less reliability of proxy-reports [39,40] and reduced parent-child agreement [41]. Pediatric settings include wide age ranges, with distinctive developmental stages, characterized by different maturational issues and developmental tasks that should be study independently. Adolescents live a complex period where personal identity, autonomy and independence urge [42,43] and the impact of a chronic disease can represent an additional burden for these natural developmental challenges [44]. Also the definition of QoL must take in consideration the developmental changes, the level of language and the establishment of health and disease concepts [45].

Despite the literature related to chronic condition and QoL/HRQol, studies have predominantly relied on proxy reports (parents, teachers, health professionals), and on childhood and adolescence together, not analyzing the influence of age on the outcomes, nor children and adolescents separately, as single groups [7,46]. A recent systematic review (1994-2014) has precisely concluded that there is a widespread utilization of developmentally appropriate QoL instruments, but an inconsistent approach to age group specificities and a less frequent use of both self and proxy reports [38]. To our knowledge, further research is need on the psychosocial impact of living with a chronic condition in the specific period of adolescence, because this is an important and relevant area of research for teachers and clinicians, both in primary care and specialties. Accordingly, the aim of this review is to examine the main sources and types of evidence in recent literature focusing on the possible association between living with a chronic condition in adolescence and the impact on quality of life (QoL), health-related quality of life (HRQoL) and psychosocial functioning. Specifically, to identify and summarize the most frequently addressed outcomes in literature referring to the risk of impairment in QoL/HRQoL and in psychosocial functioning, and to determine possible research needs.

METHODS

This systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [47].

Search strategy and study selection

A comprehensive systematic search was conducted in the electronic databases PubMed (US National Library of Medicine), EBSCO Host and PsycINFO. The keywords used for reference tracing were derived from Medical Subject Headings (MeSH), EBSCO Thesaurus and in combination with key terms used in other reviews [5,7, 48-53]. The following sets of keywords were then used and combined (AND operator): 1) "chronic illness" OR "chronic disease", 2) "quality of life" OR "health-related quality of life" 3) "psychosocial, factors"; 4) "adolescent". This search strategy was used for all databases, with slight adaptations to fit in different web interfaces. Finally, reference lists from other review articles and included studies were hand searched to find additional studies.

Two reviewers independently screened all titles and abstracts and the final papers included in this review represent a consensual reflection of the inclusion/exclusion decisions made by both reviewers.

Eligibility criteria and data extraction

To be eligible for inclusion only papers who meet the following three criteria were considered, defined according to the types of participants, studies, comparisons and outcome measures [47]. First, the studies had to include adolescents with a chronic disease (and no restrictions were considered concerning different diagnosis), ranging from 13 to 18 years old. This age range was chosen combining both definitions of The DISABKIDS Group Europe [54] and the developmental stages of Erikson's theory of psychosocial development [43,44,55]. Second, studies had to be original quantitative research papers, peer reviewed, published between 2010 and 2015 and written in English, Portuguese or Spanish. Third, the eligible studies had to show associated results between chronic illness or chronic disease terms and QoL or HRQoL, as well as psychosocial factors outcomes. At least, studies had to include one of the following quantitative measures: quality of life; health-related quality of life; psychosocial adaptation, functioning; psychological adaptation/functioning/adjustment (depression and/or anxiety); social adaptation/functioning/adjustment; and, social support.

The several QoL core domains (physical, emotional, social and school functioning) and the total scores were considered, because QoL is multidimensional in nature and diverse QoL questionnaires provide a profile instead of a single index [48]. Also both generic and disease-specific instruments were included, as well as self- or proxy-reports.

Moreover, the authors further excluded all duplicates, research employing unappropriated instruments or methodology regarding the associations under consideration (e.g. ambiguous variables under study, poor construct validity, drawing conclusions without statistical support) and qualitative research. There were no restrictions regarding the format and source of interventions, as well as for randomized controlled trials (RCTs) or types of comparisons.

Data extraction was developed, according with the PRISMA statement for reporting systematic reviews [47,56], based on the following variabels: 1) bibliographic references (author(s), year of publication and country); 2) methods (date of data collection, study design, setting, psychosocial domains assessed and respectively dimensions, name of instruments used for assessing outcomes); 3) sample characteristics (population, diagnostic, type of study: cases or case/controls, age in years, age range, sample size); and, 4) outcomes (main key associations/effects found).

Generally, relevant disparities were found in data collection, sample size, methods, procedures, analysis and contexts of the several studies, that difficult direct comparison of results among the studies. Because of such diversity of metrics and outcome variables, it was not possible to apply statistical criteria to the studies and for that reason it was not appropriate to conduct a meta-analysis of the results.

Data synthesis

This review analysed and organised the main results most frequently addressed by the literature, taking into account the previous data extraction items. The outcomes were presented in a general term designed as psychosocial domains assessed, clustered into 3 groups: 1) risk of impairment in QoL/HRQoL related to chronic condition; 2) risk of impairment in psychological functioning related to chronic condition; 3) risk of impairment in social functioning related to chronic condition. Additionally, within each group the results were grouped according to the type of association with the outcomes: *Significant higher risk*;

significant lower risk; and, *no significant differences*, and taking into account the type of the study research design. Only outcomes and results concerning the specific age range from 13 to 18 years old and the selected measures were considered.

RESULTS

Study selection results

A total of 377 potentially relevant papers (after removing duplicates) were identified in the literature search and in additional hand searches. After the screening of titles and abstracts by two independent investigators according to the defined inclusion criteria, 212 studies were excluded. The reasons for exclusion were not having the specific target age/population (*n*=158), not being relevant to the study objective (*n*=50) and not possible to access full-text (*n*=3). The remaining 165 eligible studies were reviewed, which resulted in the inclusion of 18 studies in the present review. Figure 1 shows the flowchart of the studies as well as the reasons for exclusion and Table 1 presents the general detailed information concerning each study.

[Insert Figure 1- Flowchart of studies]

[Insert Table 1 – Detailed of included studies]

Geographical allocation and Research designs

Table 2 summarizes the main features of the retrieved papers.

Regarding the geographical allocation, ten studies were conducted in Europe (two from: Belgium [68,69], Portugal [60,66] and Spain [58]; one from: Hungary [59], The Netherlands [63], Russia [74] and Germany [62]), six in North/South America (four from the United States of America [61,65,64,71], one cross-national study including the United States of America and Puerto Rico [67], one from Chile [57]), one in Asia (China) [72] and one in Australasia (Australia) [73]. The studies took place mostly in a clinical setting (*n*=16), one was conducted in a summer camp, and one did not report such information.

Concerning the research designs, one study had a double-blind placebo-controlled condition [67], one study was mixed prospective and case-control [63], one study was prospective pre-post condition [59], two studies were mixed longitudinal and case-control [68,69], seven studies were mixed cross-sectional and case-control designs [58,60-

62,65,66,72], five were cross-sectional [57,64,71,73,74], and one was descriptive/exploratory [70].

[Insert Table 2 – Summary of the main features of the retrieved papers]

Participant characteristics and type of studies (cases or case/controls)

The majority of the studies (*n*=17) used national population [57-66,68-74] and only one was transnational using cases from United States of America and Puerto Rico [67]. Concerning the diagnosis, fourteen studies focused on a single diagnosis [57,58,60-65,67-70,71,73], and four had mixed groups of diagnosis [59,66,72,74]. In total, the 18 studies examined 4,101 adolescents aged 13-18 years and the majority of the studies used broader age ranges, but reported independent results for different age groups (*n*=11) [57-63,65,66,70,71] while others focused on the specific adolescent's developmental stages (*n*=7) [64,67-69,72-74] (detailed information specifically concerning the included diagnosis and ages are presented in Additional File 1).

Regarding the type of studies, six out of eighteen studies used cases without controls [57,64,70,71,73,74], while others used several different control conditions, such as only healthy control groups (*n*=7) [59-61,66,68,69,72], both healthy and chronic illness control groups (*n*=2) [63,65], healthy population's normative data (*n*=2) [58,67], and chronic condition population's normative data (*n*=1) [62] (detailed information specifically concerning the included condition used in each study, taking into account the nature of its design, is showed in Additional File 2).

Outcome measures

To assess children's and adolescents' psychosocial domains, the majority of the included studies used self-reported measures (*n*=17) [57-66,68-74], including some studies with a multi-informant approach (including proxy-reports from parents and/or teachers) (*n*=9) [57,58,60,61,64-66,71]. In addition, nine out of eighteen studies only assessed quality of life (QoL) or health-related quality of life (HRQoL) [57-59,65,67,70-72,74] and others assessed QoL/HRQoL and additionally psychosocial domains (*n*=7) [60-64,66,69] or only psychosocial domains (*n*=2) [68,73]. Concerning the instruments, the majority of the studies included generic measures [57-63,67,68,70-73] and some used disease-specific measures

[64,65,69,74] (detailed information specifically concerning the outcome measures is showed in Additional File 3).

Risk of Impairment in HRQoL/QoL, Psychological Functioning and Social Functioning related to Chronic Condition

Ten studies reported *significant higher risk* of impairment in HRQoL/QoL [57,61-67,69,72] three presented *significant lower risk* [58,59,74], and three *no significant differences* [60,70,71]. Concerning psychological functioning, five studies showed a *significant higher risk* of impairment [61,64,66,69,73], while two indicated *no significant differences* [60,62]. Finally, regarding social functioning two studies found a *significant higher risk* of impairment [60,69], and another one a *significant lower risk* [68]. The detailed results are presented in Table 3.

[Insert Table 3 – Main results and Risk of Impairment in HRQoL/QoL, Psychological Functioning and Social Functioning]

DISCUSSION

In the present review and concerning the geographical allocation, the majority of the included studies were done in clinical settings and in Europe and North America. No studies from low- and middle-income countries were included (taking into account the classification of The World Bank Group in 2016), despite the fact that there are strong reasons to believe that, in such countries, adolescents living with a chronic condition are likely to have a high impact on their psychosocial functioning. Moreover, because data from the Non Communicable Diseases (NCD) Global Status Report (WHO, 2014) indicates that particularly in those countries, and contraire to common perception, deaths due to NCDs are overtaking those from infectious diseases, representing almost three quarters of all NCD deaths (28 million), and 82% of the 16 million premature deaths. In addition, lower-income countries generally have a minor capacity for the prevention and control of NCDs. Thus, this under-representation of research might result in restricted conclusions, however, the results help to better estimate the changes in adolescents' psychosocial outcomes, regarding chronic condition.

Most of the included studies were conducted in a clinical setting with national population, focused on adolescents with only one single diagnosis [57,58,60-65,67-71,73],

and using controls with healthy groups [59-61,66,68,69,72], or only cases (no controls) [57,64,70,71,73,74]. Concerning the design, it was found a preponderance of cross-sectional and mixed cross-sectional/case control studies, compared to longitudinal or cohort studies. Regarding the addressed dimensions, the majority of the studies, only assessed QoL/HRQoL [57-59,65,67,70,72,74] and some, additionally addressed psychological/social factors [60-64,66,68,69,71,73]. For that, generic appropriate measures were the most frequently applied, in accordance with previous literature, evidencing a general utilization of developmentally appropriate QoL instruments [39]. For assessing adolescents' psychosocial domains, most of the studies used only self-reported measures [57-66, 68-74], although others followed a multi-informant approach (including proxy-reports from parents and/or teachers) [57,58,60,61,64-66,71]. These results may indicate that contrary to suggestions in the literature [17,32,37,75,76], it was expected to find a higher widespread inclusion of a multi-informant approach, in the present study, but, on the other hand, suggestions to include self-reports seem to be taken into account. Thus, reinforcing the importance to "give voice" to young people with a chronic condition [35,36].

With respect to the period of age of the included studies, only some focused on samples with the specific adolescent's developmental stage [64,67-69,72-74] and the majority used wide ranges (from children to young adults), but presented independent and separate results for each age group [57-63,65,66,70,71]. However, it must be highlighted that during the study selection phase of the present review (and considering the eligible studies), a high number of studies were rejected (*N*=91), precisely because they did not present separate data for different age groups, considered the results/conclusions within extensive age ranges, or combined childhood and adolescence together. Thus, such findings reinforce other research indicating that there is an inconsistent approach to age group specificities, and studies analyzing psychosocial factors in adolescents as a single/independent group are still lacking and are most needed [7,38,42,43,46,53]. Specially, because the present review also observed that age seemed to be a risk factor for maladjustment with worse outcomes for older adolescents [59,66] than younger ones, and, this was expected taking into account that adolescents live a complex period of their lives, where several unique transformations take place (urge for personal identity, autonomy and independence) [42-45]. To have a chronic condition in this period can represent an additional burden for those natural developmental challenges [66,73],

compromise adherence to clinical procedures and difficult the grief and loss process [57]. It may be argued that measuring the extension and duration of the impact of the disease and to isolate this period of age appeared to be a challenging task, mainly because older children and adolescents are probably less willing to participate in clinical studies, or had no studies specifically designed for their age [63].

In the present review most of the included studies point out a *significant higher risk* of impairment in HRQoL/QoL [57,61-67,69,72], in psychological functioning [61,64,66,69,73] and in social functioning [60,69], following the direction already described in the literature [2-8]. Nonetheless, other studies presented contradictory results. For QoL/HRQoL and psychological functioning some studies reported *no significant differences* [60,62,70,71] and, for QoL/HRQoL and social functioning *significant lower risk* of impairment [58,59,68,74]. Concerning this last category, the reported satisfactory (or even moderate to high) outcomes found for adolescents living with chronic conditions can be explained taking into account reported protective factors, mainly social dimensions/peer relationships (in adolescents with Pediatric Intestinal transplantation - IT, Congenital Heart Disease - CHD, Juvenile Idiopathic Arthritis - JIA, Oncology Disease - OD and Diabetes Mellitus Type I - T1DM), but also gender, less disease severity and higher socio-economic status (in adolescents with Asthma - AS, T1DM and Epilepsy - EP). Another clarification can be made, considering that the need to “fit with peers” or the denial of disease-related problems may result in favorable social responses in self-reports [68,70]. Despite controversial findings, disease-specific factors, such as physical ability, pain, subjective burden of medication use [63], diagnosis [59,64,72,74], severity of the disease [65,69,74], school absence [61,63] and illness perception [73], seem to play a relevant role for HRQoL. On the other hand, non-disease factors, namely anxiety/depression [70], gender [68,73,74], age [57,66,74], socioeconomic status [64,74]), quality of peer relationship [68], social interaction/social support [59,60,62,69], parents support [59,73], also showed to be crucial predictors for HRQoL.

The controversial results described above show a tendency already reported in research, pointing out contrary and inconclusive results, including both an increased risk of poor outcomes [2-8] , no significant risk, or, a possible successful adaptation [10]. Such variability can be explained taking into account that the responses of living with a chronic condition are heterogeneous and quite variable, depending on several specific individual/contextual factors [11]. Furthermore, in spite of the effort to organize the

information concerning chronic conditions [7,27,77], there are still several definitions of chronic diseases (including various health conditions and degrees of severity), as well as numerous instruments used to assess HRQoL/QoL and psychosocial factors. Such heterogeneity is evident in the included studies: different diagnosis and degrees of disease's severity, diverse instruments (both general and disease specific) and several addressed measures as well as ways to assess it (self-reports, proxy-reports, multi-informant approach). Facing this scenario, it can be pointed out the need to continue efforts to find consensual procedures, in order to allow more cross-culturally research and accurate comparisons among studies, in order to better help planning interventions. Moreover, taking into account the heterogeneity observed, the present findings reinforce the need to keep an individualized framework and a comprehensive approach to inherent potential protective/risk factors. Once these are more amenable to be implemented, compared to disease-related parameters (e.g.: diagnosis, degree of severity, treatments, medication), which are often more difficult to change. Thus, studies and interventions should focus not only on physical/objective health parameters [69], but also and more frequently on subjective health parameters, as well as on the limitations in daily activities due to the disease, in order to improve HRQoL and implement more psychosocial care in these age group [59,62,65,74]. Social support (from peers and parents), peer relationship and mental health (taking into account gender and age differences) were stressed out in the present review, and can be considered potentially relevant factors to focus while planning interventions.

These suggestions follow the same direction comprised in The Ottawa Charter [78] for health promotion, suggesting the need to develop personal skills and to enable people to increase control over and improve their health. In addition, also with the Global Noncommunicable Diseases (NCD) Action Plan, proposing to focus on the underlying social determinants through people-centred primary health care and universal health coverage [79], and with the common policy priorities for Health 2020 [22] stressing out the need to empower people and create resilient communities. Therefore, interventions should be planned focusing on the individualized and specific assessment of the adolescent with a chronic condition [74], based on a global health-care system, which includes an interdisciplinary network approach, aiming to attend general health needs, guiding into lifestyle behaviors and giving support to adolescents in the transition to adult life, when changing into other healthcare system takes

place [32,80]. Psychosocial interventions should focus as well on improving HRQoL [57], moderating the impact of the disease and increasing well-being (namely social support), working on coping strategies and family functioning [66].

Implications for future research, policies and clinical practice

To summarize the data from this review allows us to have a global perspective and to propose some hypotheses, potentially useful as a framework for future research, policies and clinical practice.

First, following the tendency already reported in research, a significant number of studies from the present review suggest that living with a chronic condition increases the impairment in HRQoL/QoL, psychological and social functioning (although contradictory outcomes were found). In spite of the efforts to organize diverse information concerning chronic conditions found in the literature, the present study still demonstrates a pronounced heterogeneity and diverse assessment procedures, reinforcing the need to continue to pursuit that goal. Facing such heterogeneity, pediatric healthcare services should focus on an individualized framework to routinely assess the HRQoL, its determinants and psychosocial dimensions of adolescents with a chronic condition, mainly through self-report and additionally with parent reports (multi-informant approach) [71].

Second, the present study shows that only a few studies focused on specific samples of adolescence ages, and it could be argued that exists a substantial difficulty to assess and consider adolescence as an independent age group with developmental specific needs, different from other age periods. Accordingly, pediatric healthcare services may need to enhance a higher focus on such specific age [7,42,43,46,53], especially given the increased risk during this developmental period [63,65,66,73]. In future research and clinical practice it could be relevant to increase the participation of youth not only in their own disease process, but also in a wider health promotion structure. Considering to be good interpreters of their "world" and needs [36], adolescents can help to complement quantitative data with qualitative crucial informations [81], such as ideas to improve the instruments of assessment, medical/treatment procedures, clinical settings and social interaction with health professionals, teachers, parents and peers. Qualitative research can be useful to meet such goal [82], although it is still an emerging developing area. Moreover, adolescents can additionally benefit from more interactive social participation and help others who are struggling to better

cope with a chronic disease, through Youth Mentoring and Development Programs and for example [83].

Third, in the assessment process, it is important to focus less on the diagnostic categories and disease-related factors, and more on the real burden that the disease might have on psychosocial dimensions (non disease-related factors) [59,69,74]. In addition, to identify specific domains of impaired psychosocial functioning can help healthcare professionals to enable a systematic and comprehensive assessment of adolescent's psychosocial needs, to conduct a strategic multidisciplinary response of psychosocial care [62], and to plan resources in order to increase its cost-effectiveness [74]. The present study pointed out the role of social support (from peers and parents), peer relationship and mental health as possible protective factors. In forthcoming research it would be essential to enlighten the role of such factors and to implement related interventions and evaluate their efficacy, which already started in literature, but are not often conducted [59,84]. In addition, and relying on the idea of The Asset Model to promote salutogenic resources to improve coping abilities [85,86], it is also important to draw attention to other protective factors that predict positive outcomes recognized in the literature, such as resilience [87] or self-regulation [88]. Surely, much can be learn from resilient and self-regulate adolescents, in terms of clinical and practical relevant lessons and strategies to support the ones who struggle.

Fourth, the link between living with a chronic condition in adolescence and the direct effects in psychosocial health appears to be very complex, and wider effects have not been systematically studied, thus, further case-control and longitudinal studies are needed. Such studies could focus on relevant aspects that can bring bias on the results, such as the identification of individual adolescent's protective/risk psychosocial factors, the process of adaptation to the disease and the moment of the diagnosis (early childhood – hypothesis of better adaptation *vs.* late in adolescence). A closer analysis on countries' health-care systems and policies to cope with chronic conditions, could bring an additional contribution to explain the heterogeneity and contradictory of the present results.

Strengths and Weaknesses of this study

Some limitations in the present study and in review levels should be acknowledged. First, the present review was exclusively based on English, Portuguese and Spanish language

articles, therefore, a language bias might be present. However, it can be argued that the potential impact of studies published in other languages may be minimal, as the majority of the publications in widely accessible journals are in English. Second, given the heterogeneity of the metrics used by the studies it was not possible to use quantitative meta-analytic methods, nor identifying statistical patterns. Also the diverse measures may had result in different methodological operationalization of the constructs. Third, as the included studies were mainly cross-sectional, establishing causal inferences was limited. Furthermore, despite the fact that most studies present a higher impact of a chronic condition in HRQoL/QoL, contradictory results were found, foreseeing that probably are dependent on countries' health policies and responses for psychosocial support and adaptation to chronic diseases in adolescence. Thus, the generalization of the present findings are considerably limited by the singularity of the health paediatric systems of each country. Thus, it may be suggested that an appropriate way to ascertain whether a chronic condition impacts HRQoL/QoL and psychosocial functioning identifying inherent protective factors, is to implement more consensual procedures and to intensify the gathering of empirical evidence from long-term cohort studies, particularly across the challenging life events during adolescence. Despite these limitations, the present study gives a rough approximation of the consequences of living with a chronic condition in the HRQoL/QoL and psychosocial functioning of adolescents, and helped to better estimate the outcome changes in these age group. Recognizing similar evidences in the literature, the present review reinforces the need to continue pursuing previous goals in research and, in addition, points out other relevant areas for forthcoming studies. Consequently, the results have important clinical implications that could guide interventions.

Conclusions

In the present review the majority of the included studies were conducted in Europe and North America, in a clinical setting, with adolescents presenting only one single diagnosis, using cross-sectional and mixed cross-sectional/case controlled designs, and only cases or controls with healthy groups. The assessment was mainly focused on QoL/HRQoL through self-reported measures. Most of the included studies point out a significant higher risk of impairment in HRQoL/QoL, psychological and social functioning, although contradictory results were found, following the direction already described in the literature. Wide age ranges

(presenting separate results for each age group) were mostly employed, and only some studies focused on the specific adolescent's developmental stage, foreseeing difficulties in isolating this specific age and observing a considerable inconsistent approach to age group specificities.

Facing this results, it can be argued that in spite of efforts in research to organize information concerning chronic condition, heterogeneity in the assessment is still observed, reinforcing the need to continue working towards consensual procedures, that allow more accurate comparisons among studies, and to better help planning effective interventions. The significant higher risk of impairment and the contradictory results observed are in the same direction as evidenced in the literature. Such findings emphasize Sir Michael Marmot's idea suggesting that even if conclusions were no different than before, they need to be said again [89], bringing an additional challenge for researchers and clinicians to rethink what has been done, and to find more effective ways to implement previous knowledge to practice, into interventions that could better help these adolescents. To routinely assess psychosocial factors within an individualized framework, to considerer adolescents as a single/independent group, to emphasize a comprehensive approach to inherent potential protective factors, and to increase the participation of youth in their own disease adaptation process and in health promotion in general are highly suggested. Furthermore, can be pointed out as directions that enable multidisciplinary responses to improve HRQoL and implement more psychosocial care in these age group.

Additional Files:

Additional File 1. Participant characteristics: included diagnosis and ages.

Additional File 2. Control condition and Comparison Group Composition.

Additional File 3. Outcome measures.

List of abbreviations

AS - Asthma; CHD - Congenital Heart Disease; EP – Epilepsy; HRQoL – Health-related Quality of Life; JIA - Juvenile Idiopathic Arthritis; MeSH - Medical Subject Headings; OD - Oncology Disease; PIT - Pediatric Intestinal transplantation; QoL – Quality of Life; T1DM - Diabetes Mellitus Type I; WHO – World Health Organization.

Ethics approval and consent to participate

None sought.

Competing interests

The authors declare no further financial interests or potential conflicts of interest.

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Author's Contributions

TS and MGM coordinate and conceived the study and design, developed a systematic review protocol, draft and authored the manuscript. TS and MGM conducted the bibliographic search, the screening of titles/abstracts and the extraction and codification of data from all studies. Study outcomes were summarized by TS and MGM participated in interpretation of data and helped to draft manuscript revisions. CS, IL and MCM participated in the study design, interpretation of the data, and helped to draft significant manuscript revisions. All authors have read and approved the final manuscript.

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Figure VII-5-1. Flowchart of studies

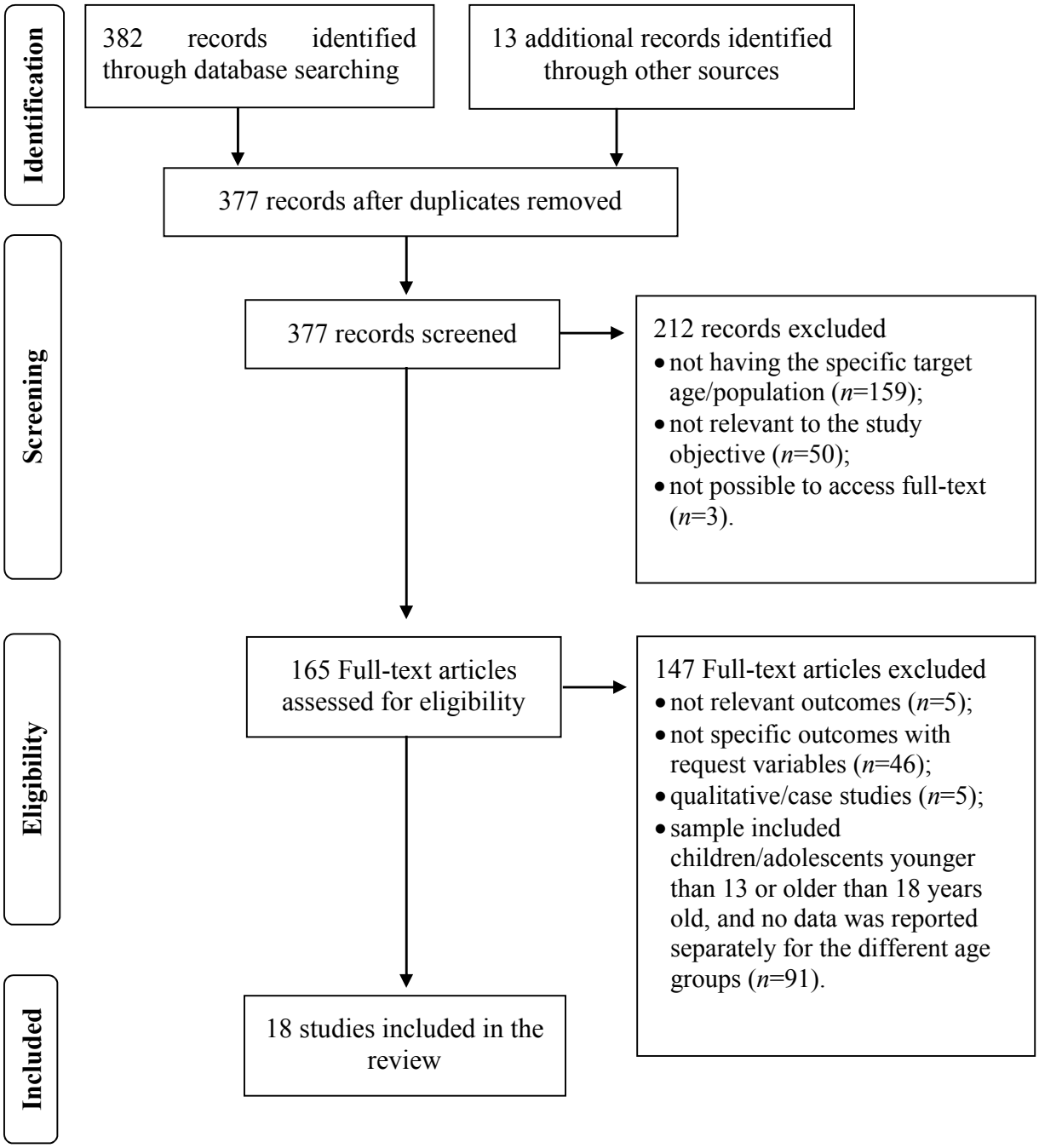

Table VII-5-1. Details of included studies

Authors, date of publication; Country. (Date of data collection)	Study Design; Setting; Population	Diagnostic*; Type of studies (cases or case/controls)	Sample Size (n)	Age in years (M±S)/ Range (age groups)	Psychosocial domains assessed (dimensions): Measures used to access outcomes**	Risk of Impairment		
						QoL/ HRQoL	Psychological Functioning	Social Functioning
Alba et al., 2013 [57]. Chile. (2010-2011)	Cross-sectional; Clinical; Children + adolescents + parents	Pediatric Liver Transplant (PLT); Only Cases, no Controls	**Total sample n=49** **Only 13-18Y: n=15** Cases 15 adolescents with Pediatric Liver Transplant	**Total sample:** 14.6±1.3 **Range:** 02-18 (02-04; 05-07; 08-12; 13-18) Y	• **HRQL (PHF, EMOF, SOF, SCHF):** PedsQL 4.0 report (Pediatric Quality of Life Inventory)[1]. *Note: EMOF, SOF and SCHF were clustered together as a psychosocial health outcome.*	**a**	----------	----------
Andres et al., 2014 [58]. Spain. (2012-2013)	Cross-sectional and case-control; Clinical; Children + adolescents + adults/caregivers	Pediatric Intestinal transplantation (PIT); Cases *vs.* Controls	**Total sample n=31** **Only 13-17Y: n=7** Cases: adolescents with Pediatric intestinal transplantation + Controls: normative population.	**Total sample:** M=10.2 **Range:** 0-29 (0-04; 05-07; 08-12; 13-17; >18) Y	• **QoL - 0-4Y:** Preschool Children's Quality of Life Questionnaire – TAPQOL[1]. • **HRQL (PWB, PSWB, SE, FAM, FRI, SCH) – 04-17Y:** KINDL-R, versions *Kiddy-Kindl* (04-07Y); *Kid-Kindl* (08-12Y) and *Kiddo-kindl* (13-17Y)[1]. • **QoL - >18Y:** SF-36v2 (Short-Form 36)[1]. • **QoL and Stress level – parents:** SF-36; CBI[1].	**b**	----------	----------
Békési et al., 2011 [59]. Hungary. (2008, 2 months between Time 1 and Time 2).	Prospective pre-post (comparative data from time 1 and time 2); Non-Clinical (summer camp); Children + Adolescents.	Oncology disease (OD), Diabetes (T1DM) and Juvenile Idiopathic Arthritis (JIA); Only Cases, no Controls.	**Total sample n=115** **Only >14Y: n=51** Cases: 14 adolescents with oncology disease + 24 adolescents with diabetes + 13 adolescents with JIA.	**Total sample:** 13.3±2.2 **Range**: 10-18 (>14; <14) Y.	• **HRQL (PWB, PSWB, ME, SPE, AUT, PRHL, FINR, SSP, SCHE, SAC, BUL):** KIDSCREEN-52[1].	**b**	----------	----------

Carona, Moreira, Silva, Crespo & Canavarro, 2014 [60]. Portugal. (2010-2011).	Cross-sectional and case-control; Clinical; Children + adolescents + parents.	Cerebral palsy (CP); Cases *vs.* Controls	**Total sample n=214** **Only 13-18Y:n=104** Cases: 48 adolescents with CP + Controls: 56 healthy adolescents	**Total sample:** 12.3±2.8 **Range:** 08-18 (08-12; 13-18) Y	• **Social Support (SSS; ACSS):** Satisfaction with Social Support Scale for Children and Adolescents (SSSS)[1]. • **Psychological adjustment (PSYCSYM, PROS, EMSY, PPROB):** Strengths and Difficulties Questionnaire (SDQ)[1]. • **HRQoL (INDE, EMO, SOINC, SOEXC, PHL, TREAT):** DISABKIDS-37[1].	**c**	**c**	**a**
Cortina et al., 2010 [61]. United States of America. (2005-2006).	Cross-sectional and case-control; Clinical; Children + adolescents + and parents/teachers.	Eosinophil-Associated Gastrointestinal Disorders (EGID); Cases *vs.* Controls	**Total sample n=108** **Only 13-18Y: n=19** Cases: 9 adolescents with EGID + Controls: 10 adolescents without acute or chronic illness.	**Total sample:** 8.3±4:4 **Range**: 02-18 (2-4; 5-7; 8-12; 13-18)Y.	• **Psychological symptoms (INTP, EXTP, BESY, ADSK, SCHP):** Behavior Assessment System for Children–Parent Report Scale/Teacher Report Scale (BASC–PRS/TRS)[1]. • **Depressive symptoms (TOTDEP, NMO, INTERP, INEF, ANH, NEGSE):** Children's Depression Inventory (CDI)[1]. • **Anxiety symptoms (TOTANX, PHS, HAV, SOANX, T/R, SOM/AUT, PERF, ANXC, HUM/R, PERF, SEPP):** Multidimensional Anxiety Scale for Children (MASC)[1]. • **HRQoL (PHF, EMOF, SOF, SCHF, PSYCO):** Pediatric Quality of Life Inventory TM (PedsQL)-Parent and child report forms[1].	**a**	**a**	----------
Elsenbruch, Schmid, Lutz, Geers, & Schara, 2013 [62]. Germany. (2009-2011).	Cross-sectional and case-control; Clinical; Children + adolescents + young adults.	Duchenne muscular dystrophy (DMD); Cases *vs.* Controls	**Total sample n=50** **Only 13-16Y: n=11** Cases: adolescents with DMD + Controls: population's normative data for children and adolescents with different chronic health conditions.	**Total sample:** 15.4±0.6 **Range:** 08-23 (08-12; 13-16; 17-23) Y	• **HRQL (TOTHRQoL, INDE, EMO, SOINC, SOEXC, PHL, TREAT):** The DISABKIDS questionnaire[1]. • **Depression Symptoms:** The Depression Inventory for Children and Adolescents (Depressions-Inventar für Kinder und Jugendliche-DIKJ)[1].	**a**	**c**	----------
Haverman et al., 2012 [63]. The Nederlands. (2009-2010).	Prospective and case-control; Clinical; Children + Adolescents.	Juvenile Idiopathic Arthritis (JIA); Cases *vs.* Controls	**Total sample n=152** **Only 13-18Y: n=248** Cases: 75 adolescents with JIA + Controls: 148 Dutch norm population + 25 children/adolescents with other chronic health conditions.	**Total sample:** 13.0±3.4 **Range:** 06-18 (06-07; 08-12; 13-18) Y.	• **Functional ability and discomfort:** Childhood Health Assessment Questionnaire (C-HAQ)[1]. • **HRQL (PHF, EMOF, SOF, SCHF):** Pediatric Quality of Life Inventory (PedsQL™) 4.0 Generic Core Scales[1].	**a**	----------	----------

Herzer, Denson, Baldassano, & Hommel, 2011 [64]. United States of America. (NR).	Cross-sectional; Clinical; Adolescents + parents.	Inflammatory bowel disease (IBD). Only Cases, no Controls.	**Total sample n=62** Cases: adolescents with IBD.	**Total sample:** 15.4±1.4 **Range**: 13-18Y	• **HRQL-adolescents (TOTHRQoL, GWB, EMOF, SOF, BIM):** IMPACT-III[2]. • **Depressive symptoms (NMO, INTERP, INEF, ANH, NEGSE:** Children's Depression Inventory (CDI)[1]. • **HRQL-parents (COM, MEDC, ROLF, EMOD):** Pediatric Inventory for Parents (PIP)[1]. • **Pediatric Crohn's Disease Activity Index – PCDAI[2].** • **Lichtiger Colitis Activity Index – LCAI[2].**	**a**	**a**	----------
Mellion et al., 2014 [65]. United States of America. (2004-2008).	Cross-sectional and case-control; Clinical; Children + adolescents + parents.	Congenital Heart Disease (CHD) (Patients in 3 CHD severity categories: mild, biventricle-BV, and single ventricle-SV); Cases *vs.* Controls	**Total sample n=1909** **Only 13-17Y:n=756** Cases: 513 adolescents with CHD and with various severity categories + Controls: 243 healthy adolescents and adolescents with other 4 chronic diseases (end-stage renal disease-ESRD, obesity, asthma, and diabetes).	**Total sample:** NR Cases: 15.1±1.6 Controls: NR **Range:** 08-18 (08-12; 13-18) Y	• **HRQL (TOTHRQoL; PHSS: PHF; PSYSOS: EMOF, SOF, SCHF):** Pediatric Cardiac Quality of Life Inventory (PCQLI)[2]. *Note: PHSS includes PHF and EMOF, SOF and SCHF were clustered together as a psychosocial health outcome.*	**a**	----------	----------
Moreira et al., 2013 [66]. Portugal. (2009-2012)	Cross-sectional and case-control; Clinical; Children + adolescents + parents	Diabetes (T1DM), Asthma (AS), Epilepsy (EP), Cerebral Palsy (CP), Obesity (OB); Cases *vs.* Controls.	**Total sample n=964** **Only 13-18Y:n=446** Cases: 51 adolescents with diabetes + 133 adolescents with asthma + 53 adolescents with obesity + 39 adolescents with epilepsy + 42 adolescents with cerebral palsy + Controls:128 dyads with healthy children/adolescents	**Total sample:** **NR** Cases: 12.4±2.8 Controls: 11.75±3.25 **Range:** 08-18 (08-12; 13-18) Y	• **HRQoL (general score):** KIDSCREEN – 10[1]. • **Psychological adjustment (internalizing, externalizing):** Strengths and Difficulties Questionnaire (SDQ)[1]. • **HRQoL of parents (overall, social, psychological, physical, and environmental):** Portuguese version of the EUROHIS-QOL-8 (for parents)[1].	**a**	**a**	----------

Olsen et al., 2012 [67]. United States of America + Puerto Rico. (2002-2005).	Double-blind placebo-controlled study (3 weeks) and a Multi-center study; Clinical; Adolescents (only through parent-report).	Manic or mixed episode associated with Bipolar Disorder (BD); Cases *vs.* Controls	**Total sample n=161** Cases: 54 adolescents using placebo + 107 adolescents using Olanzapine + Controls: population values	**Total sample:** 15.2±1.3 **Range:** 13-17Y	• **HRQL (PHSP; PSYSOS; Psychosocial scales: FAMAC, PARIEMO, MH, SEST, BEV, ROLSEB, PARIT, FAMCOE; Physical scales: BPAIN, GH, PHF, ROLSPH).** The Child Health Questionnaire Parent Form 50 (CHQ) [1].	**a**	----------	----------
Rassart et al., 2012 [68]. Belgium. (2009 , 9 months between Time 1 and Time 2).	Longitudinal and case-control (comparative data from time 1 and time 2); Clinical; Adolescents.	Congenital Heart Disease (CHD); Cases *vs.* Controls	**Total sample n=832** Cases: 429 adolescents with CHD + Controls: 403 healthy adolescents.	**Total sample:** 16.3±1.2 **Range:** 14-18Y	• **Identity identification** Identity Development Scale[1]. • **Peer relationship Quality (QCOM, TRU, ALIEN)** Inventory of Parent and Peer Attachment[1].	--------	----------	**b**
Vanhalst et. al, 2013 [69]. Belgium. (2009 , 18 months between Time 1 and Time 3).	Longitudinal and case-control (three time comparative data); Clinical; Adolescents.	Congenital Heart Disease (CHD); Cases *vs.* Controls	**Total sample n=832** Cases: 429 adolescents with CHD + Controls: 403 healthy adolescents	**Total sample:** 16.3±1.2 **Range:** 14-18Y	• **Loneliness** University of California Los Angeles Loneliness Scale[1]. • **Depressive symptoms** 20-item Center for Epidemiologic Studies Depression Scale[1]. • **HRQoL (CARDS, PPHAP, TANX, COGPC)** Pediatric Quality of Life Inventory 3.0 (self-report version of the cardiac module and only some subscales)[2].	**a**	**a**	**a**
Velasco, Martín. Díez, Pérez, & Amigo, 2012 [70]. Spain. (NR).	Descriptive and Exploratory; Clinical; Adolescents.	Diabetes mellitus type 1 (T1DM); Only Cases, no Controls.	**Total sample n=126** **Only 13-17Y: n=53** Cases: adolescents with Diabetes mellitus type 1.	**Total sample:** 11,6±2,7 **Range**: 06-17 (06-12; 13-17) Y	• **HRQoL (MOB, SCA, UAC, PDIS, ANX, DEP).** Spanish version of EQ-5D-Y (The EUROQOL Group)[1]. • **Health-status perceived perception** Visual Analog Scale (VAS)[1].	**c**	----------	----------

Vetter, Bridgewater, & McGwin, 2012 [71]. United States of America. (2009-2010).	Cross-sectional; Clinical; Children + Adolescents + parents.	Variety of primary chronic pain conditions (CPC); Cases *vs.* Parent reports.	**Total sample n=99** **Only 13-18Y: n=60** Cases: adolescents with different chronic pain conditions + parents.	**Total sample:** 13.2±2.4 **Range:** 08-17 (08-12; 13-18) Y.	• **HRQL-children, adolescents (PHF, EMOF, SOF, SCHF).** Pediatric Quality of Life Inventory (PedsQL™) 4.0 Generic Core Scales[1]. *Note: EMF, SOF and SCHF were clustered together as a psychosocial health outcome.* • **Pain assessment** Pain intensity: Pediatric Pain Questionnaire (PPQ)[1]. • **HRQL-parents (PHF, PRL, SRL, SOF, MH, EV, PAIN, GHP)** 36-item Short-Form Health Survey (SF-36)[1].	**c**	----------	----------
Wang, Wang, Wang, Xu, & Zhang, 2012 [72]. China. (2007).	Cross-sectional and case-control; Clinical; Adolescents.	Epilepsy (EP) and Asthma (AS); Cases *vs.* Controls	**Total sample n=237** Cases: 85 adolescents with epilepsy + 81 adolescents with asthma + Controls: 71 healthy adolescents.	**Total sample:** 15.2 ± 1.1 **Range:** 14-18Y	• **QoL (PHF, RPH, BPAIN, GH, VIT, SOF, REMO, MH, HT, OVQoL)** Short-Form 36-item Health Survey (SF-36) [1].	**a**	----------	----------
Williams, Sharpe, & Mullan, 2013 [73]. Australia. (NR).	Cross-sectional; NR; Adolescents.	Diabetes mellitus type 1 (T1DM); Only Cases, no Controls	**Total sample n=61** Cases: adolescents with Diabetes mellitus type 1	**Total sample:** 14.6±1.3 **Range:** 13-18Y	• **Self-management activities** Summary of Diabetes Self-Care Activities Questionnaire[2]. • **Illness perception (Identity and Consequences)** The illness perception questionnaire (IPQ)[1]. • **Attitudes and behaviours associateed with anorexia and bulimia nervosa** The eating attitude test[2]. • **Apprehension about receiving negative evaluation, avoidance of being evaluated and the expectation of being negatively evaluated** Fear of Negative Evaluation (FNE)[1]. • **Adolescents' perceptions of diabetes-specific family support** Diabetes Social Support Questionnaire – Family Version (DSSD)[2]. • **Depression symptoms** Child Depression Inventory (CDI)[1]. • **Anxiety symptoms** Spence Children's Anxiety Scale (SCAS)[1]. • **Blood glucose readings** Glycaemic control.	--------	**a**	--------

Zashikhina & Hagglof, 2014 [74]. Russia. (2002).	Cross-sectional; Clinical; Adolescents.	Chronic physical illnesses: Diabetes type 1 (T1DM), asthma (AS), and epilepsy (EP); Only Cases, no Controls.	**Total sample n=146** Cases: 50 adolescents with diabetes type 1 + 49 adolescents with asthma + 47 adolescents with epilepsy.	**Total sample:** NR Cases: Diabetes *M*=14.2 Asthma *M*=14.3 Epilepsy *M*=14.9 **Range:** 13-16Y	• **QL in Diabetes (DIABLS, DIABIMP, DIABW, GSROH)** Diabetes quality of life questionnaire for youths (DQOLY)**[2].** • **QL in Asthma (TOTAST, ASTSYEMO).** Pediatric asthma quality of life questionnaire (PAQLQ)**[2].** • **HRQL in Epilepsy (TOTHRQOL, EPIMP, MEM/C, ATTEP, PHF, STG, SS, SCHBE, HP)** Quality of life in epilepsy inventory for adolescents (QOLIE-AD-48)**[2].**	**b**	----------	----------

NR - Not Reported

a – Significant Higher Risk of Impairment; b – Significant Lower Risk of Impairment; c – No Significant Differences

1 – Generic measure; 2 – Disease-specific measure.

* AS - Asthma; BD - Bipolar disorder; CP - Cerebral Palsy; CHD - Congenital Heart Disease; CPC - Chronic Pain Conditions; T1DM - Diabetes Mellitus Type I; DMD - Duchenne Muscular Dystrophy; EGID - Eosinophil associated gastrointestinal disorders; ESRD - End-Stage Renal Disease; EP - Epilepsy; HRQoL – Health-related Quality of Life; IBD - Inflammatory Bowel Disease;; JIA - Juvenile Idiopathic Arthritis; OB – Obesity; OD - Oncology Disease; PIT - Pediatric Intestinal transplantation; PLT - Pediatric Liver transplant; QoL – Quality of Life.

** ACSS - Activities connected to social support; ADSK - Adaptive skills; ALIEN – Alienation; ANH – Anhedonia; ANX - Anxiety; ANXC - Anxious coping; ASTSYEMO - Asthma symptoms and emotional reaction to asthma; ATTEP - Attitutes towards epilepsy; AUT – Autonomy; BEV – Behavior; BESY - Behavioral Symptoms; BIM - Body Image; BUL – Bullying; BPAIN - Bodily Pain; CARDS - Cardiac symptoms; COGPC - Cognitive problems and communication; COM – Communication; DEP – Depression; DIABIMP - Diabetes impact; DIABLS - Diabetes Life satisfaction; DIABW - Diabetes-related worries; EMO-Emotion; EMOD - Emotional distress; EMOF - Emotional functioning; EMOSY - Emotional symptom; EPIMP - Epilepsy impact; EV - Energy/Vitality; EXP - Externalizing problems; FAM – Family; FAMAC - Family activities; FAMCOE - Family coesion; FINR - Financial resources; FRI – Friends; HAV - Harm avoidance; HP - Health perception; HRQoL - Health-related quality of life; HT - Health Transition; HUM/R - Humiliation/rejection; IND – Independence; INEF – Ineffectiveness; INTERP - Interpersonal problems; INTP - Internalizing problems; ME - Moods and Emotions; MEM/C - Memory/Concentration; MH - Mental Health; MOB – Mobility; GH - General Health; GHP - General Health Perception; GSROH - General self-rating overall health (single item); GWB - General Well-being; QCOM - Quality of communication; QoL - Quality of life; MEDC - Medical care; NEGSE - Negative self-esteem; NMO - Negative Mood; OVQoL - Overall Quality of life; PAIN – Pain; PARIEMO - Parental impact-emotional; PARIT - Parental impact-time; PDIS - Pain/discomfort; PERF – Perfectionism; PERF - Performing in public; PHF - Physical Functioning; PHL - Physical limitations; PHS - Physical symptoms; PHSS - Physical health summary score; PPROB - Peers problems; PSYCSYM - Psychopathological symptoms; PSYSO – Psychosocial; PSYSOS - Psychosocial health summary score; PSWB - Psychological Well-being; PROS – Prosocial; PRHL - Parent Relations and Home Life; PRL - Physical Role Limitation; PPHAP - Perceived physical appearance; PWB - Physical Well-being; REMO - Role-emotional; ROLF - Role functioning; ROLSEB - Role/Social/Emotional/Behavioral; ROLSPH - Role social/physical; RPH - Role-physical; SAC - Social Acceptance; SCA - Self-care; SCHF - School functioning; SCHE - School Environment; SCHP - School problems; SES - Socioeconomic Status; SOEXC - Social exclusion; SOINC - Social inclusion; SOF - Social functioning; SPE - Self-perception; SRL - Social Role Limitation; SSP - Social Support and Peers; SEST - Self-esteem; SCH – School; SOANX - Social anxiety; SOM/AUT - Somatic/autonomic; SEPP - Separation panic; SSS - Satisfaction with social support; STG – Stigma; SS - Social support; SCHBE - School Behaviour; TANX - Treatment anxiety; TOTAST - Total score and how asthma interferes with activities; TOTANX - Total anxiety score; TOTHRQoL - Total score HRQoL; TOTDEP - Total depression score; T/R - Tense/restless; TREAT – Treatment; TRU – Degree of trust; UAC - Usual activities; VIT – Vitality.

Table VII-5-2. Summary of the main features of the retrieved papers

Research Design	**Number of Studies**
Double-blind placebo-controlled condition	1
Mixed prospective and case-control	1
Prospective pre-post condition	1
Mixed longitudinal and case-control	2
Mixed cross-sectional and case-control designs	7
Cross-sectional	5
Descriptive/exploratory	1
Geographical allocation	
EU (Belgium, Portugal, Spain, Hungary, The Netherlands, Russia and Germany)	10
North America (United States of America)	4
South America (United States of America and Puerto Rico, Chile)	2
Asia (China)	1
Australasia (Australia)	1
Participant Characteristics	
National population	17
Transnational population (cases from United States of America and Puerto Rico)	1
Single diagnosis	14
Mixed groups of diagnosis	4
Independent results for different age groups	11
Specific adolescent's developmental stages	7
Only cases (and no controls)	6
Healthy control groups	7
Healthy and chronic illness control groups	2
Healthy population's normative data	2
Chronic condition population's normative data	1

Table VII-5-3. Main results and Risk of Impairment in HRQoL/QoL, Psychological Functioning and Social Functioning

HRQoL/QoL	
HRQoL/QoL - Significant Higher Risk of Impairment	
A cross-sectional study from Chile with adolescents with PLT showed that all the group of school-age patients reported poor or very poor psychosocial HRQOL, especially determined by school functioning. As patients advance in age, physical HRQOL seemed to worsen (though not significantly), and it was experienced as poor in adolescents (over 13 years old), with girls having a better physical and social functioning HRQOL than males (p=.03 and .04, respectively).	[57]
A mixed cross-sectional and case-control design study from United States of America (USA) with children and adolescents with EGID reported lower HRQoL than controls, based on both parent and youth reports. Parents additionally reported significantly more missed school days in the past month (M=4.91 vs. 0.50; p < .001), as well as in the past year (M=23.18 vs. 2.83; p<.001), than controls.	[61]
A mixed cross-sectional and case-control design study from Germany with adolescents with DMD, showed significantly differences in HRQOL when compared with published normative data, for the dimension Social Inclusion - SOINC (p<.001) and had significant reductions in physical aspects of HRQOL, despite scores on all other dimensions showed no significant differences. The impairment of the Social Inclusion dimension, points out that adolescents may be at higher risk for a poor social relationship and inclusion, reduced positive social relationships and/or reduced positive feedback from others, when compared with published normative data from adolescents with various other chronic health conditions. This study stresses out that DMD may not always be associated with impaired psychosocial HRQOL, although progressive physical impairment leads to reduced physical aspects of HRQOL.	[62]
A mixed prospective and case-control study from The Nederlands with children and adolescents with JIA reported that adolescents had significantly lower HRQoL in almost all domains compared to either healthy controls, or with children/adolescents with other chronic health conditions, independent of pediatrician-reported disease activity status or disease duration. Functional ability, patient-reported pain, school absence, and the subjective burden of medication use, appear to be factors strongly related to impair HRQOL in all patients. When compared to the Dutch healthy norm population, adolescents reported significantly lower HRQoL scores on all scales, except for emotional functioning and large effect sizes were found for the total score and physical health. Compared to the chronic health condition group, only the score for physical health was significantly lower and considering different age groups, both children and adolescents showed a significantly lower score on HRQoL in almost all domains, but older children reported fewer problems than younger children.	[63]
A cross-sectional study from United States of America (USA) with adolescents with IBD showed evidence that the adolescent's depressive symptoms fully mediates the relationship between parent distress and several dimensions of HRQoL (i.e., General Well-Being, Emotional Functioning, Social Functioning, and Total HRQoL). This mediation can be observed after statistically controlling for the impact of disease severity, IBD diagnosis, and significant demographic parameters on HRQoL. Significant negative correlations between disease severity and each dimension of HRQOL were also found (General Well-Being, r=−.47, p<.01; Emotional Functioning, r=−.39, p<.01; Social Functioning, r=−.27, p<.05; Body Image, r=−.32, p=.01; Total HRQOL, r=−.45, p<.01).	[64]

A mixed cross-sectional and case-control design study from United States of America (USA) with children and adolescents with CHD showed that patient and proxy-reported PedsQL scores (Total, physical health, and psychosocial health summary scores), in both child and adolescent groups were significantly lower compared with healthy controls (p<.0001 for all comparisons), and, similar PedsQL scores were obtained when comparing with other conditions, such as ESRD, AS and OB. Proxy-reported PedsQL scores were similar to those in the ESRD, OB, and T1DM groups, but significantly higher than those in the AS group. Significant differences were as well observed among disease severity categories for all scores (p<.01): children and adolescents with Biventricle - BV and Single-ventricle - SV conditions had significantly lower HRQOL than healthy controls, and similar HRQOL as patients with other chronic pediatric diseases. In the mild CHD group, HRQoL was generally similar to the diabetes group, but better than the end-stage renal disease and asthma groups, according to both patient and proxy reports. HRQoL in the Single-ventricle - SV population was generally similar to the ESRD, AS, and OB, but worse than the T1DM group, according to both patient and proxy reports. [65]

A mixed cross-sectional and case-control design study from Portugal, with children/adolescents with different clinical diagnosis (T1DM, AS, EP, CP and OB) showed that the effects of age category for each condition revealed significant differences between children and adolescents for the groups with diabetes and asthma, and for those, with no medical condition. Children reported higher levels of QoL than adolescents for all the conditions, thus adolescents showed worse adjustment than younger children. Self-reported QoL levels were lower in adolescents for almost all conditions and lower QoL was also reported by the parents of adolescents with all conditions. In addition, children/adolescents with obesity reported decreased QoL and poorer psychological adjustment, compared with their healthy counterparts and children with other conditions, particularly those with asthma and diabetes. This study suggest a higher risk for maladjustment during adolescence. [66]

A double-blind placebo-controlled condition study from United States of America (USA) and Puerto Rico, with adolescents with BD (but only through parent-report) showed that at baseline both treatment groups had lower scores for HRQoL in psychosocial domains (p=.009), rather than physical factors, when compared to healthy population values. The same result was observed at the end point (following 3 weeks of treatment) and adolescents with bipolar disorder continued to exhibit deficits in several aspects of psychosocial summary scale (p=.017), but not on the Physical summary scale. Although the above results comparing with the population's mean, there was an improvement over time across on most subscales in both groups, and the adolescents in the olanzapine group exhibited significantly greater improvement in the Psychosocial summary score from baseline to end point, compared with those in the placebo group (10.2 *vs*. 6.2 point change, p<.05), specifically in subscales Behavior, Family activities, and Mental health, and, also a reduction of manic symptoms was associated with improvement in HRQoL values. Nevertheless, after 3 weeks of treatment, deficits in several aspects of psychosocial functioning were still present, indicating that additional pharmacologic and psychosocial interventions may be necessary to further improve functional outcomes. [67]

A mixed longitudinal and case-control study from Belgium with adolescents with CHD reported that patients and controls did not differ in loneliness levels at Time 1, suggesting normalcy rather than deviance in the social and emotional lives of adolescents with Congenital Heart Disease. Nevertheless, substantial individual differences in the course of loneliness were observed: specifically, five loneliness trajectories were identified (i.e., chronically high, high decreasing, moderate stable, low increasing, and stable low). These trajectories were meaningfully differentiated on depressive symptoms and several domains of perceived health. Generally, adolescents in the chronically high loneliness trajectory reported the poorest perceived health, whereas adolescents in the low stable trajectory reported the opposite pattern and neither the development of loneliness, nor the emergence of trajectories was moderated by sex or disease complexity. In sum, adolescents in the at-risk loneliness trajectories (i.e., chronically high, high decreasing, and low increasing) experienced more depressive symptoms, cognitive problems, cardiac symptoms and had more difficulties in communicating with clinicians and accepting their disease-specific physical appearance. [69]

A mixed cross-sectional and case-control design study from China with adolescents with EP and AS showed that the total QOL score and scores of the 8 subscales were significantly different compared to healthy controls (p<.05). The total QOL score (p<.001) and scores of the subscales role-physical (p=.001), general health (p=.008), role-emotional (p<.001) and mental health (p=.042) were also significantly different between controlled and uncontrolled epilepsy groups (p<.001). For the adolescents with AS, the total QOL score and scores of 4 subscales (physical functioning, role-physical, general health and vitality) were significantly different, comparing with healthy controls (p<.005 for all). The total QOL score (p<.001) and scores for the subscales physical functioning (p=.003), role-physical (p<.001), bodily pain (p=.001), vitality (p=.013), role-emotional (p<.001), mental health (p=.002) were significantly different between controlled and uncontrolled asthma groups. The total QoL score of adolescents with epilepsy were significantly different from those with asthma (p<.05 for all) reporting poorer QoL, regardless the remission and disease stage. Also the group of adolescents with epilepsy showed lower results than the group with asthma, concerning emotional and mental health. [72]

HRQoL/QoL - Significant Lower Risk of Impairment

A mixed cross-sectional and case-control design study from Spain with adolescents with PIT showed that from the total age groups (0-29Y), the adolescent group and their parents were the most satisfied concerning overall QoL. Physical and psychological well-being was also very positively and these scores increased with age. Specifically in adolescents aged 13-17Y, the overall QOL score was higher than for their controls, particularly in the social dimensions, such as family and friends. This does not match the parents' answers, which scored this dimension highly but were in general more pessimistic, except for chronic disease perception. Teenagers also scored lower values for the school dimension, like the general population, in contrast to their parents, who considered it more positively and really appreciate that the child is able to attend school. [58]

A prospective study from Hungary with children and adolescents with OD, T1DM and JIA, focusing on the comparisons of scores of *pre* and *post* moments, showed that the experience in a therapeutic recreation camping program had a positive impact on HRQoL in the three groups of diagnosis, independently of the type of disease, age, gender, and previous camp experience. Relationships and School Environment subscales showed positive changes in adolescents over 14Y and quality of interaction with parents had also a significant improvement. [59]

A cross-sectional study from Russia with adolescents with T1DM, AS and EP showed that a high proportion of adolescents with diabetes, asthma, and epilepsy reported moderate to high levels of HRQoL. However, the most relevant domains affecting HRQoL were related to both disease-specific (severity) and non-disease factors (gender and SES). Gender was the most prominent predictor of HRQoL in all three studied groups, while disease severity predicted HRQoL only in the diabetic group and to some extent in the asthma group. Age was a significant predictor only in the epilepsy group. The directions of associations related to higher HRQoL were: less disease severity, higher SES, and older age. In the specific group of adolescents with Asthma or Diabetes SES predicted HRQoL, and the ones with Diabetes expressed more concerns regarding the impact of the disease and life satisfaction. Gender differences were also reported: girls showed significantly more Disease-Related Worries than boys ($p<0.05$), and in the group of Asthma, girls had significantly lower scores on the Symptom subscales ($p < 0.001$) and Overall score ($p < 0.01$), thus, reporting a more impairment in QoL. In the group of adolescents with epilepsy, compared to boys, girls showed higher self-perceived QoL on the Memory/concentration subscale ($p < 0.05$) and for the Total score ($p < 0.01$), but lower on Attitude toward epilepsy subscale ($p < 0.05$). [74]

HRQoL/QoL - No Significant Differences

A mixed cross-sectional and case control study from Portugal with children and adolescents with CP reported no significant differences in their psychological maladjustment, and in a mediation model, both dimensions of psychological maladjustment were found to mediate the link between social support and HRQL, but these indirect effects were not conditional upon age or gender. [60]

A descriptive/exploratory study from Spain with adolescents with T1DM showed no significant differences were found for the dimensions Mobility, Self-care, Usual activities and Pain/discomfort, according to age and gender groups. The most significant dimension for the all population was anxiety/depression, affecting in a higher significant level the adolescent group (p=.004). Additionally, no significant correlation was observed among the level of HB1Ac (glycated hemoglobin) and the self-perceived health status (p>.05). [70]

Regarding self- and proxy-report agreement, a cross sectional study from United States of America (USA) with children and adolescents with a variety of CPC showed that for the total study sample ($p = 0.008$), there was no statistically significant difference ($p <0.01$) between the patient self-reported and the parent proxy-reported HRQoL scores, stating a moderate patient-parent agreement ($ICC \approx 0.60$) for overall health status and for the physical and psychosocial health domains on the PedsQL™ across the entire age range, as well as in the younger (8-12 year) and older (13-17 year) age groups. None of the independent variables: age, gender, race, duration of chronic pain duration, chronic pain intensity, household income, parental marital status, and parental total SF-36v2 score, were consistently significantly associated with the absolute difference between the patient self-reported and the parent proxy-reported Total Scale Score on the PedsQL™. Despite no consistent statistically significant differences were found, it was observed a pattern of parents reporting lower mean HRQoL scores than their children, especially for the Psychosocial Health Summary Scores. [71]

Psychological Functioning related to chronic condition

Psychological Functioning related to chronic condition - Significant Higher Risk of Impairment

A mixed cross-sectional and case control study from United States of America (USA) with children and adolescents with EGID reported higher overall depressive symptoms (p<.001), higher values for anhedonia (p<.001), negative mood (p<.01), and negative self-esteem (p<.001), when compared with controls. For total anxiety symptoms, no differences were found between the groups, with the exception of higher physical symptoms of anxiety (p<.05), as well as autonomic arousal (p<.01), than controls. Parents of children and adolescents diagnosed with EGID reported higher frequencies of internalizing (p<.001) and externalizing symptoms (p<.001), when compared with controls. Children and adolescents (reported by parents) showed less developed social skills (p<.001), and, reported by teachers, more frequent internalizing symptoms (p<.05), comparing with controls. Based on parent report, a higher percentage of children and adolescents (45.3%) demonstrated levels of internalizing symptoms in the clinical range $\chi 2$ (1, N=107) = 31.52, p<.001. Based on teacher report, a higher percentage of children and adolescents with EGID had symptoms on the Somatization Scale in the clinical range (20%) compared with controls (0%), $\chi 2$ (1, N =108) = 7.77, p<.001. [61]

A cross-sectional study from United States of America (USA) with adolescents with IBD, found a significant difference concerning the diagnosis and also on General Well-Being, t(59)=−2.91, p<.01, Body Image, t(60)=−2.39, p<.01, and Total HRQOL, t(58)=−2.22, p<.01, with adolescents diagnosed with Crohn's disease reporting lower HRQOL than those with ulcerative colitis. Approximately 15% of these adolescents experienced depressive symptoms falling in the clinical range (≥ 13), consistent with other groups of older children and adolescents with IBD. Body image was also found to be significantly different based on household income, F(8, 49)=2.86, p=.01, with adolescents from higher household income homes endorsing greater body image. [64]

Another mixed cross-sectional and case control study from Portugal with children and adolescents with different clinical diagnosis (T1DM, AS, EP, CP and OB) showed worse psychological adjustment, with more internalizing problems (for the adolescents with T1DM or CP), when compared with controls. The adolescents with OB, EP or CP, reported more internalizing problems than those with no medical condition, AS, or T1DM. Comparing the effect of age for each condition, children reported fewer internalizing problems than those with no medical condition, AS or T1DM. For externalizing problems, children/adolescents with EP reported more problems than those with no medical condition, AS, T1DM, or CP. In addition, children/adolescents with obesity reported poorer psychological adjustment compared with their healthy counterparts and children with other conditions, particularly those with AS and T1DM. General results suggested a high risk for maladjustment during adolescence. [66]

A mixed longitudinal and case-control study from Belgium with adolescents with CHD reported that adolescents in the at-risk loneliness trajectories (i.e., chronically high, high decreasing, and low increasing) experienced more depressive symptoms, cognitive problems, cardiac symptoms and had more difficulties in communicating with clinicians and accepting their disease-specific physical appearance. [69]

A study from Australia with adolescents with T1DM showed that illness perceptions and developmental issues together accounted for 42 and 60% of the variance in anxiety and depression, respectively. Fear of Negative Evaluation and Eating Attitudes independently predicted current levels of depressive symptomatology and current levels of anxiety were predicted only by FNE and family support. On the other hand, illness identity predicted higher anxiety and depression, such that higher illness identity was associated with higher levels of anxiety and depression. Girls reported higher levels of anxiety than boys and no relationship was found between age of onset, current age, or illness duration with anxiety and depression. For illness representations, adolescents who reported a greater number of symptoms associated with diabetes (i.e. fatigue, numbness and sweating), and the ones who viewed their diabetes as having serious consequences, had higher levels of both depression and anxiety. Additionally, higher Fear of Negative Evaluation was associated with greater levels of anxiety and depression. For developmental challenges, unhelpful eating attitudes were associated with higher levels of anxiety and depression and higher levels of family support were significantly associated with lower levels of anxiety (but not depression). Additionally, higher FNE was associated with greater levels of anxiety and depression [73]

Psychological Functioning related to chronic condition - No Significant Differences	
A mixed cross-sectional and case control study from Portugal with children and adolescents with CP reported no significant differences in their psychological maladjustment. In a mediation model, both dimensions of psychological maladjustment (*i.e.* internalizing and externalizing problems) were found to mediate the link between social support and HRQL, and these indirect effects were not conditional upon age or gender. Additionally, it was showed that there were no significant differences in self- and parent-reported psychological maladjustment between children/adolescents with CP and their healthy peers.	[60]
A mixed cross-sectional and case-control design study from Germany [66] with adolescents with DMD, showed no clinically relevant depressive symptoms.	[62]
Social Functioning related to chronic condition	
Social Functioning related to chronic condition - Significant Higher Risk of Impairment	
A mixed cross-sectional and case control study from Portugal with children and adolescents with CP reported lower levels of social support than their healthy peers. In a mediation model, the link between social support and HRQL was mediated by both 2 dimensions of psychological maladjustment (*i.e.* internalizing and externalizing problems), and these indirect effects were not conditional upon age or gender.	[60]
A mixed longitudinal and case-control study from Belgium with adolescents with CHD reported that patients and controls did not differ in loneliness levels at Time 1, suggesting normalcy rather than deviance in the social and emotional lives of adolescents with Congenital Heart Disease. Nevertheless, substantial individual differences in the course of loneliness were observed: specifically, five loneliness trajectories were identified (i.e., chronically high, high decreasing, moderate stable, low increasing, and stable low). These trajectories were meaningfully differentiated on depressive symptoms and several domains of perceived health.	[69]
Social Functioning related to chronic condition - Significant Lower Risk of Impairment	
A study from Belgium with adolescents with CHD reported that these adolescents were generally found to be as competent as controls in establishing a strong identity. Supportive peer relationships positively influenced the process of identity commitment made, and girls scored higher than boys on peer relationship quality. Nevertheless, patients report higher peer relationship quality than controls.	[68]

AS - Asthma; BD - Bipolar disorder; CP - Cerebral Palsy; CHD - Congenital Heart Disease; CPC - Chronic Pain Conditions; T1DM - Diabetes Mellitus Type I; DMD - Duchenne Muscular Dystrophy; EGID - Eosinophil associated gastrointestinal disorders; ESRD - End-Stage Renal Disease; EP - Epilepsy; HRQoL – Health-related Quality of Life; IBD - Inflammatory Bowel Disease; JIA - Juvenile Idiopathic Arthritis; OB – Obesity; OD - Oncology Disease; PIT - Pediatric Intestinal transplantation; PLT - Pediatric Liver transplant; QoL – Quality of Life.

Table VII-5-4. Additional File 1. Participant characteristics: included diagnosis and ages

Diagnosis	Single Diagnosis	Mixed Diagnosis	Study
Gastrointestinal Conditions:			
Eosinophil associated gastrointestinal disorder (EGID)	X		[61]
Inflammatory Bowel Disease (IDB)	X		[64]
Pediatric Liver transplant (PLT)	X		[57]
Pediatric Intestinal transplantation (PIT)	X		[58]
Cardiac Condition:			
Congenital Heart Disease (CHD)	X		[68]
Congenital Heart Disease (CHD)	X		[65]
Congenital Heart Disease (CHD)	X		[69]
Diabetes Mellitus Type I (T1DM)	X		[70]
Diabetes Mellitus Type I (T1DM)	X		[73]
Neurological Diseases:			
Cerebral Palsy (CP)	X		[60]
Duchenne Muscular Dystrophy (DMD)	X		[62]
Pediatric Rheumatology Condition:			
Juvenile Idiopathic Arthritis (JIA)	X		[63]
Psychiatric Disease:			
Bipolar Disorder (BD)	X		[67]
Primary Chronic Pain Conditions (CPC)	X		[71]
Oncology Disease (OD) + Diabetes Mellitus Type I (T1DM) + Pediatric Rheumatology Condition: Juvenile Idiopathic Arthritis (JIA)		X	[59]
Neurologic disease: Epilepsy (EP) + Asthma (AS)		X	[72]
Diabetes Mellitus Type I (T1DM) + Asthma (AS) + Neurological Disease: Epilepsy (EP)		X	[74]
Diabetes Mellitus Type I (T1DM) + Neurological Diseases: Epilepsy (EP), Cerebral Palsy (CP) + Obesity (OB)		X	[66]

Ages (Years Old)	Specific Adolescent Development Stage	Broader Age Ranges	Study
13-16Y	X		[74]
		X (08-23Y)	[62]
13-17Y		X (0-29Y)	[58]
		X (08-18Y)	[65]
	X		[67]
		X (06-17Y)	[70]
13-18Y		X (02-18Y)	[57]
		X (08-18Y)	[60]
		X (02-18Y)	[61]
		X (06-18Y)	[63]
	X		[64]
		X (08-18Y)	[66]
		X (08-17Y)	[71]
	X		[73]
14-18Y		X (10-18Y)	[59]
	X		[68]
	X		[69]
	X		[72]

AS - Asthma; BD - Bipolar disorder; CP - Cerebral Palsy; CHD - Congenital Heart Disease; CPC - Chronic Pain Conditions; T1DM - Diabetes Mellitus Type I; DMD - Duchenne Muscular Dystrophy; EGID - Eosinophil associated gastrointestinal disorders; ESRD - End-Stage Renal Disease; EP - Epilepsy; IBD - Inflammatory Bowel Disease; JIA - Juvenile Idiopathic Arthritis; OB – Obesity; OD - Oncology Disease; PIT - Pediatric Intestinal transplantation; PLT - Pediatric Liver transplant.

Table VII-5-5. Additional File 2. Control condition and Comparison Group Composition

Type of studies (cases or case/controls)	Design	Study
Only Cases, no controls	Cross-sectional	[57,64,71,73,74]
	Descriptive/exploratory	[70]
Healthy control groups	Mixed cross-sectional and case-control	[60,61,66,72]
	Mixed longitudinal and case-control	[68,69]
	Prospective pre-post condition	[59]
Healthy and chronic illness control groups	Mixed cross-sectional and case-control	[65]
	Mixed prospective and case-control	[63]
Healthy population's normative data	Mixed cross-sectional and case-control	[58]
	Double-blind placebo-controlled condition	[67]
Chronic condition population's normative data	Mixed cross-sectional and case-control	[62]

Table VII-5-6. Additional File 3. Outcome measures

Assessed Dimensions			Self-Report	Proxy-report	Study
HRQoL/QoL	**Psychological Factors**	**Social Factors**			
X[1]			X*	X*	[57]
X[1]			X*	X*	[58][3]
X[1]			X		[59]
X[2]			X*	X*	[65]
X[1]				X	[67]
X[1]			X		[70]
X[2]			X		[74]
X[1]			X		[72]
X[1]			X*	X*	[71][3,4]
X[1]	X[1]	X[1]	X*	X*	[60]
X[1]	X[1]		X*	X*	[61]
X[1]	X[1]		X		[62]
X[1]	X[1]		X		[63][4]
X[2]	X[1]		X*	X*	[64][3]
X[1]	X[1]		X*	X*	[66][3]
X[2]	X[1]	X[1]	X		[69]
		X[1]	X		[68]
	X[1]		X		[73][3]

[1] Generic measures - GM
[2] Disease specific measures – DSM
[3] Study that specifically assessed the Qol/HRQoL of parents using generic measures.
[4] Study that specifically assessed disease-related issues.
* Multi- informant approach (including both self and proxy-reports)

Chapter VIII

Research Phase III – Empirical Studies 6-9

Empirical Study 6

Psychosocial Profile in Portuguese Adolescents With Chronic Disease Attending An Outpatient Department In A Hospital Setting

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ABSTRACT

Living with a chronic disease (CD) in adolescence involves new multifaceted challenges. This study aims to conduct a psychosocial characterization of a group of adolescents with chronic diseases in a hospital setting, and to compare such dimensions for the total group and for different diseases. A cross-sectional study included 135 adolescents with chronic diseases (51.9% boys; 48.1% girls), having an average age of 14±1.5 years (*SD*=1.5) and attending a paediatric outpatient department in a hospital setting. Statistically significant differences were found among the different chronic diseases for the variables self-regulation (adolescents with diabetes had significantly higher competences) and multiple psychosomatic symptoms (adolescents with neurologic diseases reported significantly more complaints). Boys presented both better health-related quality of life and psychosomatic health, when compared to girls. No statistically significant differences were observed for health related quality of life, psychosomatic health, resilience and social support.

Conclusion: This findings bring important suggestions especially while planning interventions, which must take into account the promotion of a healthy psychosocial development, through an inclusive perspective (covering different chronic diseases), that concurrently take in consideration specific and gendered approaches. Such suggestions might help healthcare professionals, to better plan interventions in order to increase their effectiveness.

Keywords: Adolescence; Chronic Disease; Health-related quality of life; Psychological Adjustment; Psychosocial Development; Social Support.

List of Abbreviations

CHLN EPE	Centro Hospitalar Lisboa Norte
HRQoL	Health-related Quality of Life
QoL	Quality of Life
KIDS-10	KIDSCREEN Index
NASS	Need for Activities connected to Social Support
RES	Healthy Kids Resilience Assessment Module
SCL	Symptoms Check List-HBSC-SCL (Psychosomatic Complaints)
SR	Adolescent Self-Regulatory Inventory (ASRI)
SR-LT	Self-regulation, Long Term
SR-ST	Self-regulation, Short Term
SSS	Satisfaction with Social Support
SSSS	Scale of Satisfaction with Social Support
WHO	World Health Organization

What is Known – What Is New (Authors Summary)

What is Know

- Living with a chronic condition in adolescence can impair a healthy psychosocial development.
- Psychosocial factors have been recognized in the adolescent's health promotion.

What is New

- Adolescents with diabetes reported higher competences of self-regulation, whereas the youngsters with neurologic diseases presented worse psychosomatic health. Boys shown higher health-related quality of life and psychosomatic health, compared to girls.
- This findings might help healthcare professionals, highlighting the need to assess psychosocial variables and plan specific/gendered interventions.

INTRODUCTION

Mortality rates of several fatal chronic diseases have decreased over the past 40 years due to advances in paediatric medicine and in life expectancy [1]. It is estimated that around 10% of adolescents suffer from a chronic disease affecting daily life, and this prevalence will likely tend to further increase [2], turning into an increasing global public health concern [3].

Living with a chronic condition in adolescence, where profound bio-psycho-social changes occurs, involves a whole set of new multifaceted challenges to youth, such as learning daily routines and functioning (for example: taking medication, adherence to treatments), adopting healthy life styles, monitoring symptoms [4] and dealing with uncertainty about the disease itself and the future. It is a demanding experience for adolescents, which can affect several aspects of the individual's life, namely social, family and occupational functioning. In addition, it also involves the adjustment on multiple life domains, and the regulation of cognitions, emotions, behaviours, physiologic aspects and the interaction with others [5].

Therefore, a chronic condition in adolescence may conduct adolescents into a higher risk for a healthy psychological development [6,7], lead them to experience more adjustment difficulties [8], poor health-related quality of life (HRQoL) [9,10] and a negative impact on the general quality of life (QoL) [11]. Moreover, the diagnosis, treatment and ongoing management of chronic diseases are stressful for youth, families and healthcare professionals [3,12,13], thus, this group is doubly disadvantaged and may be more vulnerable to adverse health outcomes [14,15]. Such vulnerability is in accordance with previous research reported in Portuguese studies [16-18] and, more specifically, in the area of chronic condition [19,20].

In face of this scenario, it becomes crucial to take into account the consequences of the psychological, physical and social impact of living with a chronic disease, which can bring losses to adolescents' quality of life. Literature suggests that studies focusing on children's subjective well-being should include the associations among demographic variables (e.g.: gender, age, and socio-economic status), interpersonal characteristics (e.g.: self-perceptions, psychological well-being, mood, and emotions) and the perception of well-being and happiness [21,22]. Furthermore, the individual perception regarding the disease and its adaptation process can be changeable and moderated by gender [23]. Girls can be at a higher risk for a more compromised psychological adjustment, reporting low life satisfaction, multiple health complaints and poorer outcomes for self-rated health and health-related quality of life, when

compared with boys [24-26]. This may be explained by different internalization and externalization patterns, as well as gender-specific experiences on puberty [27,28]. Additionally, resilience can also play an important role in the adaptation to adverse health states, leading to a more acceptable quality of life [29,30].

Research that compares adolescents with and without a chronic condition, or among different conditions, has been contradictory, inconclusive, and do not confirm a direct relationship between the degree of suffering and the chronic health condition [31]. Responses are quite variable and not homogeneous, depending on various specific individual/contextual factors and on the type of condition and emerging limitations, being even worse in the presence of both [32]. In addition, the prevalence of different health conditions, namely having a greater number of concurrent health problems (3/more compared with 2), is associated with worse quality of life, as well as to the type of chronic condition [33,34]. More specifically, the results on emotional well-being and psychosocial development of these adolescents are still controversial and variable, due to the definition of chronic disease [35], the intrinsic complexity of the disease state and the numerous instruments used to assess psychological well-being [36]. In addition, reports generally focus on a single set of conditions, or on very large populations [35]. Although some evidence highlights the increased vulnerability in groups of adolescents with chronic disease, other results suggest that scores are usually much better than in healthy individuals, showing a good psychosocial functioning [36,37].

Psychosocial factors start to become much more important than physical influences as individuals age. Therefore, in the promotion of adolescents' health, a major focus was underlined on positive guidelines identifying important areas such as the perception of subjective well-being and social support (which affect HRQoL) [38,39]. Health professionals have increasingly recognized and acknowledge psychosocial variables, rather than only physical dimensions [31,40-43]. Mainly, because theoretical models show an association of multiple psychosocial factors with higher impact on adult's health [18,44]. Thus, *psychosocial* is the shorthand term for the combination of psychological and social dimensions [45], which has been widely used in literature related to health outcomes [46]. The roots of psychosocial health lie in the World Health Organization's (WHO) definition of health, as a state of complete physical, mental, and social well-being, and not merely the absence of disease and infirmity [47].

Taking into account the increasingly relevance of psychosocial domains, the present study focuses precisely on such variables, including health-related quality of life, individual symptoms of physical/psychological functioning (psychosomatic complaints), resilience, self-regulation and social support. Specifically, the aims of this study were: 1) to make a psychosocial characterization of a group of adolescents with chronic diseases; and, 2) to compare such dimensions for the total group and for the different diseases. The focus on these groups relies on the literature's evidence as the most prevalent chronic diseases in adolescence [32].

MATERIALS AND METHODS

Participants, Design and Procedure

This cross sectional study included 135 selected chronic adolescent patients (51.9% boys; 48.1% girls) with a mean age of 14 years old (*SD*=1.5), attending a clinical appointment in the paediatric outpatient department of *Centro Hospitalar Lisboa Norte* – CHLN EPE (North Lisbon Central Hospital). The majority were boys (51.9%; *n*=70), had normal weight (71.8%; *n*=94), Portuguese nationality (97.8%; *n*=132), lived in Lisbon (84.4%; *n*=114) and attended the 7^{th}-9^{th} school grades (53.3%; *n*=72). Adolescents and their parents were selected and then approached directly by their health professionals (physicians and/or nurses) during the moment of the appointment. Health professionals (paediatricians) help to identify the following applied inclusion criteria: 1) diagnosis of chronic disease (included in the specific medical appointments of diabetes, allergy and neurology); 2) age between 12 and 16 years old at the time of the study; 3) have cognitive skills to fill the questionnaire autonomously.

The participation was voluntary, the description of the study's aims and participants' rights was delivered and the informed consent required by the ethical committee was filled, by both adolescents and their parents. Data was collected using a self-reporting questionnaire after or before the medical appointment, according to the most convenient moment for all (adolescent, parents and health professional's appointment), whenever possible in an individual and more quiet medical office. Ethical approval for this study was obtained from The Ethics Committee for Health from CHLN-EPE, the institution's ethical committees (Compliance with Ethical Standards: Reference PCA-12 Nov.2012-0785).

Measures

Adolescents completed self-reporting questionnaires to assess socio-demographic, clinical and psychosocial variables. Socio-demographic and clinical variables included age, gender, geographic region, nationality, educational level (adolescents and parents), time since diagnosis and the use of special equipment and/or medication related to the chronic condition. The psychosocial variables included health-related quality of life-HRQoL (KIDSCREEN-10 Index), Psychosomatic Complaints (Scale Symptoms Check List-HBSC-SCL), Resilience (Scale Healthy Kids Resilience Assessment Module), Self-regulation (Scale Adolescent Self-Regulatory Inventory-ASRI), and Social Support (Scale of Satisfaction with Social Support-SSSS) and are all presented in more detail in Table 1.

[Table 1 near here]

Statistical Analysis

Descriptive statistics (means, standard deviation and percentage) were used to characterize the sample. Adolescents were classified by medical conditions into three groups: diabetes, allergy and neurologic diseases. All data was tested for normality prior to any analyses. The normality of the variables was tested by Shapiro-Wilk and Kolmogorov-Smirnov tests, and variance homogeneity was tested by Levene's test. ANOVA (followed by comparisons using the Bonferroni Post Hoc Test) and Student T-Test were performed to evaluate significant differences in the analysed variables among the three groups of diseases and for the total group. Kruskal-Wallis were additionally conducted when normality and the variance homogeneity of the variables were not observed. Data analysis was performed using the Statistical Package for Social Sciences (SPSS), version 22.0 for Windows. For all tests statistical significance was set at $p<0.05$.

RESULTS

Socio demographic and clinical variables

The socio-demographic and the clinical characteristics of the sample are presented in Table 2.

[Table 2 near here]

The sample included a group of adolescents divided into three subgroups of chronic diseases: diabetes (31.9%; *n*=43), allergic diseases (46.7%; *n*=63) and neurologic diseases (21.5%; *n*=29). The total group had a mean time of diagnosis of 7.5 years (*SD*=4.7), mostly take medication (65.2%; *n*=88) and generally did not use special equipment (61.5%; *n*=83) related to the chronic disease. The group of adolescents with allergic diseases reported the higher percentage of taking medication due to the disease (96.8%; *n*=61). The adolescents with diabetes showed the higher percentage of using special equipment due to the disease (97.7%; *n*=42) (e.g.: tolls related to the monitoring of blood glucose and the intake of insulin).

Psychosocial variables

The group comparisons (Table 3) showed significant statistical differences for the variables Self-regulation (Scale Adolescent Self-Regulatory Inventory-ASRI) and the group of adolescents with diabetes had a significantly higher level of self-regulation for the total score [$F(2,132 = 3.598, p=.030)$], as for the short-term regulation score [$F(2,132; 4.091, p=.019)$]. Post hoc tests indicated that, comparing with the group of adolescents with allergic diseases, the adolescents with diabetes had significant higher values both for the total score (124.7 ± 15.6 *vs.* 117.5 ± 14.7) and short-term (44.2 ± 7.0 *vs.* 40.5 ± 6.7) of self-regulation competences; and no significantly differences were found for the group of neurologic diseases. Also for the variable SCL-MC (two or more symptoms, more than once a week in the past six months) there was statistically significant differences between the different group of diseases, $\chi^2(2)=6.095$, $p=0.047$.

No statistically significant differences were found in the three subgroups of chronic diseases concerning the psychosocial variables: Health-related quality of life-HRQoL (KIDSCREEN-10 Index), Psychosomatic Complaints (Scale Symptoms Check List – HBSC-SCL), Resilience (Scale Healthy Kids Resilience Assessment Module) and Social Support (Scale of Satisfaction with Social Support-SSSS).

[Table 3 near here]

Facing the few statistic differences observed in psychosocial variables, further analyses considering the total group of adolescents were conducted for the socio-demographic and clinical variables. Results are presented in Table 4. Boys had statistically significantly higher

health-related quality of life than girls (82.43 ± 11.15 *vs*. 76.68 ± 13.21; $t(133)=2.740$, $p=0.007$). Boys also presented a statistically significantly higher health (reporting less psychosomatic complaints), when compared to girls (36.57±4.52 *vs*. 34.51 ± 4.99; $t(133)=2.523$, $p=0.013$). Concerning the use of special equipment related to the chronic disease, the group of adolescents who uses special equipment had statistically significantly higher self-regulation competences when compared to the group of adolescents who does not use special equipment (123.31 ± 15.03 *vs*. 117.77 ± 13.66; $t(133)=-2.210$, $p=0.029$).

[Table 4 near here]

DISCUSSION

The present study aimed to: 1) to make a psychosocial characterization of a group of adolescents with chronic diseases; and, 2) to compare the study's variables within the total group, and in the three chronic disease subgroups, divided according to the medical condition (asthma, diabetes and neurologic diseases). The focus on these groups relies on the literature's evidence as the most prevalent chronic diseases in adolescence [32].

A brief overview of main results shows that the majority of adolescents takes medication and, generally, does not use special equipment related to the chronic disease. Adolescents with allergic diseases present higher percentages for taking medication, and adolescents with diabetes have the higher percentages for using special equipment.

For the three chronic disease groups, significant differences were found for the variables SR and SCL-MC. Regarding SR, the group of adolescents with diabetes showed significantly higher levels of self-regulation, both for the total score and for the short-term dimension. It is also observed in these group a higher percentage of using special equipment related to the disease (e.g. insulin assessment/intake tools). Previous literature can help to explain this findings, once it is suggested that adolescents with diabetes must adhere to multiple complex daily tasks, including blood glucose monitoring, insulin administration, nutrition management, and efforts to engage in physical activities. All of these demands require high levels of self-management, a fundamental component of diabetes care, with has an important association to better metabolic control in youth [59]. Concerning SCL-MC, results indicated that the group of adolescents with neurologic diseases reported higher multiple psychosomatic health complaints, reinforcing prior studies pointing out that having a greater number of health problems (3/more compared with 2) [33,34], the type of disease and its emerging limitations

[32] can lead to worse responses. Additionally, such group of diseases are probably the ones who can present higher visible limitations, and this fact has been shown to primarily determine the adolescent's perception of the diseases' severity [36].

No statistically significant differences were found for the three chronic disease groups, concerning the psychosocial variables KIDS-10, SCL, RES and SSSS. These findings are in accordance with prior research with adolescents with chronic diseases that reported no significant associations [60,61], or when comparing different diseases showed a reasonable psychosocially functioning, a general well-adjustment, and a less severe self- perception of the disease as physicians did [36]. Although other studies have indicated a high risk of impairment in psychosocial functioning for adolescents with chronic conditions [62-64]. Thus, it reinforces the idea that the activity of the disease may not be associated to psychosocial factors and fails to reveal the perceived physical and mental quality of life of adolescents [46]. At the same time, emphasizes previous research not confirmed a direct relationship between the degree of suffering and the condition (in comparisons of adolescents with different conditions) [31,35,36]. In practice, it may difficult physicians to accurately infer the patient's perception of the disease's severity [36].

With respect to the total group of adolescents, relatively moderate to high levels of health-related quality of life and social support were found, in accordance with previous studies with adolescents with chronic conditions [37,65,66], and in a similar tendency of the national healthy population, when observing the Portuguese data [49]. Such results may be due to the fact that when assessing the quality of life in adolescents with chronic diseases, some aspects of the disease and its limitations are sometimes underestimated. Indeed, disease modifies adolescents' experiences due to treatments and limitations, and also influences the subjective perception of life, social relationships, goals, priorities and self-esteem, being one major stressful event, but it can, at the same time, promote personal maturity. Literature also suggests that developmental needs are the same for both healthy and chronically ill adolescents, probably implying the existence of a similar structure of quality of life in such population, once health, physical and mental well-being are crucial dimensions [67].

Additionally the present results indicate gender differences for the total group of adolescents, being in accordance with previous research suggesting that coping with a chronic disease is a changeable process, moderated by gender [21-23]. Boys reported a significantly

higher health-related quality of life and less psychosomatic complaints, compared with girls. Such evidence is in line with prior studies pointing out that girls can be at higher risk for a more compromised psychological adjustment, reporting poorer health/mental health outcomes, multiple health complaints and more risk-internalizing behaviours [24-28]. Lastly, the group of adolescents who uses special equipment reported higher self-regulation competences than the ones who do not use special equipment. This results may be explained because the group who uses special equipment is mostly composed adolescents with diabetes (97.7%).

Limitations and Strengths

This study has a number of limitations to be considered. The not representative sample and the cross-sectional design precludes inferences concerning causality, presenting weakness to examine the direction of the effects, therefore, plausible generalizations should take this into consideration. Longitudinal data would be needed. Finally, the group of adolescents was heterogeneous in terms of the type/severity of the disease, and findings were entirely based on adolescents' self-reports, thus, biases in perception and reporting cannot be ruled out. Regardless of these limitations, this study allows to increase the knowledge on clinical evidence and give important preliminary insights on psychosocial dimensions in a group of adolescents with chronic conditions, in a hospital setting. It offers important suggestions to help healthcare professionals, especially while planning interventions. In the future, it would be important to test these variables in a larger sample and to conduct comparisons with other chronic conditions or with different degrees of disease's severity, as well as with healthy groups of adolescents. Larger comprehension on the role of gender it is suggested because it seems to be a crucial explanatory variable, as also showed in previous research [37].

CONCLUSIONS

In conclusion, this study brings knowledge on the psychosocial impact of living with a chronic condition in a group of adolescents in a hospital setting and allowed the identification of the most vulnerable groups of adolescents considering the different diseases. It further reinforced that more than deducing psychosocial impairment mainly from the disease's characteristics, it is important to frequently assess such dimensions [31,40-43] by multidisciplinary teams, to help coping with the disease [18,43,44], regarding general health outcomes [46]. Such assessment should include the adolescent's self-perceptions [46], because

health promotion implies effective and active support for physical, psychological and social well-being of children and adolescents, matching their own needs. Furthermore, due to variable and heterogeneous responses of adjustment to a chronic disease, which depend on various specific individual/contextual factors, and on the type of condition, onset of diagnosis and emerging limitations [32].

It seems crucial to implement programs/interventions to promote a healthy psychosocial development and equal psychoeducation. Facing this study results and the previous studies that suggest both differences/similarities on psychosocial impairment when comparing different chronic diseases, it may be useful to plan inclusive interventions that concurrently include individual and gendered aspects. To rely such interventions on a more individualized assessment of each adolescent's psychosocial status could help to increase intervention's effectiveness, rather than mostly draw it from the disease's activity. More specifically, the present study emphasizes the need to focus on self-regulation skills training, with a special attention on girls as the most vulnerable group. Therefore, this study draws attention for healthcare professionals to focus on minimizing the difficulties and maximizing potential in all children with a chronic disease, involving the dimensions of psychological and social functioning, along with educational achievement [43].

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COMPLIANCE WITH ETHICAL STANDARDS

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Conflict of interest The authors declared that they have no competing interests.

Ethical approval. All procedures in the present study were performed in accordance with the ethical standards of the institutional and/or national research appropriate committee (The Ethics Committee for Health from CHLN-EPE, Reference PCA-12 Nov.2012-0785), and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Written informed consent was obtained from all individual participants included in the study (both adolescents and their parents/legal guardians). For this type of study, formal consent from adolescents under 14 years old were not required.

Author's contributions. TS and MGM conceived the study, participated in its design and coordination, draft and authored the manuscript; AM helped to perform statistical analyses, participated in interpretation of data and helped to draft manuscript revisions; CS participated in the study design, interpretation of the data, and helped to draft manuscript revisions; IL participated in the study design and helped to draft manuscript revisions; MCM participated in the study design and helped to draft manuscript revisions. All authors have read and approved the final manuscript.

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Table VIII-6-1. Psychosocial Variables

Name	Psychosocial Measure	Abbreviation (in this study)	Short Description	Alpha Cronbach
KIDSCREEN-10 Index [16,48,49]	Health-related quality of life – HRQoL	KIDS-10	• Short version of KIDSCREEN-52; • 10 items, on a 5-point Likert-type scale; • Ranges from 0 to 100; • Lower values reflect feelings of unhappiness, dissatisfaction and inadequacy. Higher values show feelings of happiness, perception of adequacy and satisfaction within adolescent's life contexts.	α = 0.83
Symptoms Check List (SCL-HBSC) [50,51]	Psychosomatic complaints (unidimensional latent trait).	SCL	• Used in the HBSC/WHO Study [57,58] • 8 items focusing on subjective physical and psychological health complaints; • Each item answered on a 5-point Likert-type response scale; • Resulting values between 1 (worst health) and 5 (best health); • Ranges from 8 to 40.	α = 0.78
Symptoms Check List (Multiple Complaints) [52]	Concerning the variable Psychosomatic Complaints (Scale Symptoms Check List – HBSC-SCL) and according to the literature, that suggests that adolescents with recurrent multiple health complaints are considered to present noticeable subjective health complaints, an additional variable named SCL-MC (Multiple Complaints) was created, composed by those adolescents who reported two or more symptoms, more than once a week in the past six months.			
Healthy Kids Resilience Assessment Module [53,54]	Resilience (2 dimensions: external and internal resources).	RES	• The present study only used the internal resources; • 18 items answered on a 4-point scale; • Ranges from 18 to 72; • Higher scores indicate higher levels of competences, protection and resilience to adversity.	α = .0.72[1]
Adolescent Self-Regulatory Inventory – ASRI [55]	Self-regulation (2 dimensions: Short term-SR-ST and Long term-SR-LT).	SR	• In this study the instrument was translated from the original English version into Portuguese language (and back translation). It was then revised by a group of specialized experts within the area and a pre-test in schools with a group of students was conducted. • 36 items answered on a 5-point Likert scale; • Ranges from 36 to 180. • Higher values indicate better competences of self-regulation.	α = .0.79[1]
Scale of Satisfaction with Social Support [39,56]	Satisfaction with social support (2 dimensions: Satisfaction with Social Support-SSS; and Need for Activities connected to Social Support-NASS).	SSSS	• Translation and adaptation for children and adolescents, of a Satisfaction with Social Support Scale for adults; • 12 items answered on a 5-point scale; • Ranges from 18 to 72; • Higher scores indicate higher satisfaction with social support (SSS) or higher satisfaction for not feeling the need to have more social support activities (NASS).	α = 0.85[1]

[1] Value for the total score of the scale.

Table VIII-6-2. Participant's socio-demographic and clinical characteristics

	Subgroups of Chronic Diseases			Total Group of CC
	Diabetes N=43	**Allergic diseases** N=63	**Neurologic Diseases** N=29	N=135
Socio-demographic Variables				
Age (years) (M±SD)	13.7±1.6	14.2±1.5	14.0±1.5	14.0±1.5
Gender (%)				
Boy	41.9	58.7	51.7	51.9
Girl	58.1	41.3	48.3	48.1
Educational Level – Adolescents (%)				
Basic 2nd Level (5th-6th Grades)	23.3	20.6	20.7	21.5
Basic 3rd Level (7th-9th Grades)	48.8	58.7	48.3	53.3
Secondary Level (10th-12th Grades)	27.9	20.6	31.0	25.2
Educational Level - Father (%)				
Basic Level (1st-9th Grades)	55.0	69,5	67,9	64.6
Secondary Level (10th-12th Grades)	27.5	23,7	17,9	23.6
Superior (or more) Level (University, Post-Graduate)	17.5	6,8	14,3	11.8
Educational Level - Mother (%)				
Basic Level (1st-9th Grades)	46.3	62,9	44,8	53.8
Secondary Level (10th-12th Grades)	34.1	24,2	34,5	29.5
Superior (or more) Level (University, Post-Graduate)	19.5	12,9	20,7	16.7
Clinical Variables				
Time since diagnosis (years) (M±SD)	5.0±3.9	8.9±4.6	8.5±4.9	7.5±4.7
Special equipment (%)				
No	2.3	93.7	79.3	61.5
Yes	97.7	6.3	20.7	38.5
Medication (%)				
No	79.1	3.2	37.9	34.8
Yes	20.9	96.8	62.1	65.2

Table VIII-6-3. Differences between the groups of adolescents with diverse chronic diseases for all psychosocial variables

	Total	**Subgroups of Chronic Diseases**			
		Diabetes	**Allergology**	**Neuropathology**	*p*
	N=135	N=43	N=63	N=29	
KIDS-10 (M±SD) [1]	79.7±12.5	80.0	79.7	79.2	0.976
SCL (M±SD) [1]	35.6±4.8	35.3	36.1	35.0	0,536
SCL-MC[2]	0.67±1.18	0.60±1.16	0.54±1.12	1.07±1.31	0.047
RES (M±SD) [1]	58.4±7.8	60.3	58.1	56.1	0.074
SR (M±SD) [1]	120.0±14.4	124.7	117.5	118.2	0.030
SR-ST	41.8±6.8	44.2	40.5	41.1	0.019
SR-LT	50.2±7.7	51.6	49.6	49.5	0.345
SSSS (M±SD) [1]	45.1±8.6	45.6	45.0	44.4	0.860
NASS	15.8±4.7	16.0	16.0	15.1	0.652
SSS	29.1±5.4	29.6	28.7	29.3	0.711

SCL - Symptoms Check List; SCL-MC - Symptoms Check List Multiple Complaints; KIDS-10 - KIDSCREEN; RES - Resilience; SR - Self-regulation; SR-ST - Self-regulation, short term; SR-LT – Self-regulation, long term; SSSS – Scale of Satisfaction with Social Support; NASS – Need for Activities connected to social support; SSS – Satisfaction with social support.

[1] Tested by ANOVA followed by Bonferroni Post-Hoc Test
[2] Tested by Kruskal-Wallis

Table VIII-6-4. Differences between gender (boys/girls) and using special equipment (yes/no) for all psychosocial variables.

	Gender			**Special Equipment**		
(M±SD)	**Boys**	**Girls**	*p*	**No**	**Yes**	*p*
KIDS-10[1]	82.43±11.15	76.68±13.21	.007	79.69±12.14	79.62±13.12	.974
SCL[1]	36.57±4.52	34.51±4.99	.013	36.00±4.89	34.90±4.73	.202
RES[1]	58.07±7.55	58.66±8.13	.663	57.70±7.64	59.40±8.04	.218
SR[1]	119.63±15.17	120.18±13.64	.824	117.77±13.66	123.31±15.03	.029
SSSS[1]	46.34±8.64	43.69±8.49	.075	44.61±7.86	45.80±9.80	.444

SCL - Symptoms Check List; KIDS-10 – KIDSCREEN; RES – Resilience; SR – Self-regulation; SS – Social Support.

[1] Tested by Independent T-Test.

Note: no statistically differences were found for the variables: age, educational level of the adolescents, educational level of the mother, educational level of the father, time since diagnosis and medication use related to disease.

Chapter VIII

Research Phase III – Empirical Studies 6-9

Empirical Study 7

The Impact of Chronic Health Conditions and Related Psychosocial Factors in Adolescence

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ABSTRACT

Background: Adolescents with chronic conditions (CC) can be more vulnerable to adverse health outcomes. This study aims to analyze the impact of living with a CC on school/peers connectedness (measured by reported participation in school and participation in social activities), and the association with key psychosocial factors (health-related quality of life - HRQoL, psychosomatic health, resilience, self-regulation, and social support).

Methods: A cross-sectional study was conducted that included 135 adolescents with chronic conditions (51.9% boys; 48.1% girls), having an average age of 14±1.5 years (*SD*=1.5). Socio-demographic, clinical, and psychosocial variables were assessed, using a self-reporting questionnaire, including the Chronic Conditions Short Questionnaire, the KIDSCREEN-10 Index, the Symptoms Check-List, the Healthy Kids Resilience Assessment Module Scale, the Adolescent Self-Regulatory Inventory, and the Satisfaction with Social Support Scale. Descriptive statistics, GLM-Univariate ANCOVA and Logistic Regression were used; all analyses were completed using IBM Statistical Package for Social Sciences (SPSS), version 22.0. The significance level was set at $p<0.05$.

Results: Thirteen to eighteen percent of the adolescents felt that CC had an impact on participation at school (PSCH) and participation in leisure time with friends (PLTF). These adolescents presented lower results for all psychosocial study variables, when compared with adolescents who do not feel affected in both areas of participation. With respect to the extent to which psychosocial variables were associated with PSCH (after controlling for age, gender, diagnosis, and education level of father/mother), self-regulation and psychosomatic health were the most important psychosocial variables to explain such association. Regarding the PLTF, social support was the sole variable explaining this association.

Conclusions: The present study brings innovation pointing out the association between the impact of living with a CC and school/peers connectedness and the relationship with several key psychosocial factors, which are not often evaluated. It is crucial to focus attention on the assessment of the impact of a CC on adolescents' lives and contexts, and to identify such vulnerable adolescents, because it may help to implement interventions focused on providing support and opportunities for a healthy youth development. Therefore, a complex and multifactorial approach that includes clinicians, schools, family, and peers is needed.

Keywords: Adolescents; Chronic Health Condition; Health-related Quality of Life; Psychosocial Factors; Psychosomatic Health; Resilience; Self-regulation; Social Support.

INTRODUCTION

Adolescence is a critical developmental stage for a positive course of future health and well being, especially in a context of living with a chronic condition. A chronic condition is often characterized by great variability: in the definition of the concept, in the assessment of its prevalence, as well as in the identification of its impact on the child or adolescent [1]. Apart from this variability, it is well recognized that it can represent a major psychosocial burden, and can contribute to the risk of a higher level of psychosocial stress [2]. Thus, adolescents with chronic health conditions can be more vulnerable to adverse health outcomes and be at a higher risk for unhealthy psychological development [3,4] and poor general quality of life [5]. Depending on specific individual/contextual factors, the adaptation responses can be quite different among adolescents. Also, the adaptation process, and quality of life, can be compromised in the presence of the type of disease/emerging limitations, along with having a greater number of health problems (3/more, compared with 2) [6]. Therefore, cumulative risks may have a strong impact and may be a threat to the adolescent's well being, particularly in the emergence of psychological symptoms [7].

Living with a chronic condition can have impact on an individual level, in the entire family system [8], and in the academic context [9,10]. It may also lead to isolation from the peer group [11], with consequences on non-academic contexts such as health and well being [12]. These negative consequences place adolescents with chronic conditions at a higher risk for poor educational, vocational, and social outcomes [13]. As age increases, and particularly in adolescence, participation in social activities, connections, and peers are crucial because they assume a major importance in the socialization process [14]. These factors also represent a powerful positive protective factor and a key component for developing healthy youth [15,16]. Peer relations and support from close friendships can play an important role in the adolescent's psychosocial development, and can have a special significance mostly when a chronic disease exists. Social connections can be a great help to cope with the disease, with the psychosocial changes, and with the lifestyle aspects of treatment regimens [17]. However, these same connections can also be a major challenge for a treatment's recommendations and for therapeutic adherence. This is because being healthy is important for "fitting in" with peers. Such participation in educational/social activities with peers, and the connections with other people/institutions, can be weakened due to various consequences of having a chronic condition in adolescence [18]. Such limitations rely on a dynamic interdependence between the

adolescent and his environment including individual, socioeconomic, and demographic factors [19] as well as psychosocial variables, more than the presence, *per se*, of the physical dimensions of the chronic condition [1,10]. As a result, addressing psychosocial dimensions assumes increasing importance for the holistic care of these children and adolescents [20-24]. There is a vast amount literature in the field of chronic conditions, including research comparing children's and parents' QoL (Quality of Life) across several conditions, and children with different conditions [25,26]. However, these studies have focused specifically on proxy reports of children and have not analyzed the influence of age-different groups (childhood and adolescence) on the outcomes [27,28]. To our knowledge, the impact of living with a chronic condition in the specific period of adolescence, focusing on connectedness and psychosocial factors, has not been evaluated often. Further research is needed because this is an important and relevant area of research for educators and clinicians, both in primary care and specialties.

Therefore, whereas connectedness can be conceptualized in multiple ways, the present study will focus on school and peers connectedness (participation at school, PSCH; and participation in leisure time with friends, PLTF). Both aspects have been shown to be associated with positive youth health outcomes. They are in line with previous studies pointing out the need to address limitations in ordinary activities of chronically ill adolescents [29], and to focus less on diagnostic categories (where more variability exists) and more on the impact that such health conditions might have on the social activities/socialization and emotional health [1]. This study will also emphasize the results of the total group of adolescents, instead of presenting different diagnoses or comparisons with healthy peers. This approach supports research suggesting the need to center on "within-group" studies to identify factors that better predict social adjustment or disease management [17]. Thus, the current study aims to: 1) identify differences in psychosocial variables (health-related quality of life, psychosomatic complaints, resilience, self-regulation and social support) among adolescents who feel that CC affects or does not affect PSCH and PLTF, 2) assess the extent to which psychosocial variables were associated with affecting or not affecting both areas of participation, and 3) identify the most relevant ones as well as those most amenable to intervention. This identification could help to facilitate the maximization of social participation of adolescents with CC. It is hypothesized that adolescents living with a CC, and feeling that CC has a higher impact on their social participation (PSCH and PLTF), can be more vulnerable to psychosocial health outcomes. It is

additionally expected that, for those adolescents feeling that the disease affects PSCH and PLTF, some psychosocial variables have a greater significant association than others.

METHODS

Participants, Design and Procedure

This cross sectional study included 135 chronic adolescents (51.9% boys; 48.1% girls) who had a mean age of 14 years (*SD*=1.5), were attending the pediatric outpatient department of a public central hospital, and had a diagnosis of neurologic diseases, allergic diseases or diabetes. The choice of these chronic conditions was based on the evidence that asthma, epilepsy, and diabetes are some of the most prevalent chronic diseases in adolescence [30]. The majority of these adolescents lived in the Lisbon area (*n*=114), attended the 7^{th}-9^{th} grades (*n*=72) and had Portuguese nationality (*n*=132). They also had 7.0 years of median time of diagnosis, generally did not use special equipment (*n*=83), and mostly took medication (*n*=88) for their chronic disease.

Prior to data collection, an ethical approval for this study was obtained from The Ethics Committee for Health and the institution's ethical committees. Using a convenience sampling technique, adolescents and their parents were selected and then were approached directly by their health professionals (physicians and/or nurses) during the different medical expertise appointments: neurology, allergic diseases, and endocrinology. The following inclusion criteria were applied: 1) diagnosis of chronic disease, which was established by a physician and also ascertained in the questionnaire; 2) ages including both groups of young teens (12-14Y) and teenagers (15-17Y), according to the definition of age ranges of the Centers for Disease Control and Prevention – CDC, and 3) to have the cognitive skills necessary to fill out the questionnaire autonomously. Following the World Medical Association Declaration of Helsinki's guidelines proposed in 2013, detailed information about the study aims and procedures was provided to all participants; those who met the inclusion criteria were invited to participate. The participation was voluntary and the agreement and informed consent required by the ethical committee was obtained, both from parents and adolescents (above 14 years old). Data were collected (whenever possible in an individual medical office) using a self-reporting questionnaire (separately for adolescents and for parents) either after or before the medical appointment, according to the most opportune moment for all (adolescent, parents and health professional's appointments). Research assistance was available to provide support whenever

necessary. Adolescents completed the questionnaire themselves, also in accordance with literature that has been gradually steering away from the practice of seeking opinion through proxy from parents or healthcare providers. The approach suggested is to ask adolescents directly about their chronic health conditions, and the impact these conditions have on their lives, since there is evidence that adolescents can provide a better explanation of their experiences [2].

Measures

Socio-demographic and clinical variables were obtained through a self-reporting questionnaire that assessed: age, gender, geographic region, nationality, height and weight, and education level (adolescents and parents). To define a chronic condition, support from the assistant pediatrician was required, and the questionnaire additionally included the question "Do you have a long-term disability, illness or medical condition (like cerebral palsy, diabetes, arthritis, or allergy) that has been diagnosed by a doctor? No/Yes". Also, the impact of a chronic health condition on the adolescents' activities was assessed by the following questions: 1) "Does your long-term illness, disability or medical condition affect your attendance and participation at school? No/Yes" (PSCH) and, 2) "Does your long-term illness, disability or medical condition affect your attendance and participation in leisure activities with friends, classmates? No/Yes" (PLTF). These questions are included as an optional package in the international study Health Behaviour in School-aged Children (HBSC/WHO) [31,32] and constitute the Chronic Conditions Short Questionnaire (CCSQ) [33]. This instrument helps to understand the psychosocial impact of chronic illnesses, and shows considerable strengths over a single question, open-ended item. Co-existing problems related to the need to take medication, and/or missing school classes, are also reported as good indicators of severity. The adolescents were also asked some specific questions related to the disease: the time since diagnosis, the use of special equipment, and the use of medication related to the disease.

The psychosocial variables were also obtained through a self-reporting questionnaire which included: health-related quality of life-HRQoL (KIDSCREEN-10 Index), Symptoms Check-List (Psychosomatic Health Complaints), Resilience (Scale Healthy Kids Resilience Assessment Module), Self-regulation (Scale Adolescent Self-Regulatory Inventory-ASRI), and Social Support (Scale of Satisfaction with Social Support-SSSS) described in Table 1.

[Table 1 near here]

Statistical Analysis

Descriptive statistics were calculated for both demographic, clinic, and psychosocial variables (means, standard deviation, and percentages) for the total group of adolescents. All data were tested for normality prior to any analyses using Shapiro-Wilk and Kolmogorov-Smirnov tests, as well as Levene's test for the homogeneity of the variance. A GLM-Univariate ANCOVA (analysis of covariance) was conducted to determine differences between adolescents who felt that CC affects or does not affect participation at school and participation in leisure time with friends on psychosocial variables; controlling for age, gender, diagnosis of chronic condition, and education level of father and mother. Later, a logistic regression was used to assess the extent to which psychosocial variables were associated with affecting and not affecting school and leisure time with friends participation. The group "not feeling affected" was used as the reference group. Adjusted and unadjusted odds ratio (OR) with 95% confidence intervals (CIs) were calculated and the significance level was set at $p<0.05$. To avoid multicollinearity in the logistic regression analysis, variables were tested and none was omitted. All statistical analyses were completed using IBM Statistical Package for Social Sciences (SPSS), version 22.0. The significance level was set at $p<0.05$.

RESULTS

The socio-demographic and the clinical variables included in the study for the total group of adolescents are presented in Table 2.

[Table 2 near here]

This study included a group of 135 adolescents having three diagnosed chronic diseases: diabetes (n=43), allergic diseases (n=63), and neurologic diseases (n=29); most of them felt that living with a CC does not affect PSCH (n=111), or PLTF (n=117).

The comparisons on all psychosocial variables, between affecting/not affecting PSCH and between affecting/not affecting PLTF, are shown in table 3. The group of adolescents who feel that CC does not affect PSCH showed a higher health-related quality of life compared to the group that felt that CC affects PSCH (82.2 ± 10.1 *vs*. 68.0 ± 15.6; $F(1,118) = 33.16$, $p <.001$). Also, those adolescents present a better psychosomatic health (36.7±3.8 *vs*. 30.3±5.8;

$F(1,118) = 42.46$, $p < .001$), higher resilience (59.0±7.4 *vs*. 55.5±9.1; $F(1,118) = 6.07$, $p = .015$), higher self-regulation competences (121.8±14.4 *vs*. 110.9±10.6; $F(1,118) = 10.78$, $p = .001$), and more social support (46.6±7.6 *vs*. 38.2±10.0); $F(1,118) = 22.72$, $p < .001$), when compared with the individuals who felt that CC affects PSCH. The group of adolescents who felt that CC does not affect PLTF reported a higher health-related quality of life when compared to the group that felt that CC affects participation (81.6±10.6 *vs.* 67.3±16.6; $F(1,118) = 22.53$, $p < .001$). In addition, those adolescents showed a better psychosomatic health (36.2±4.2 *vs*. 31.6±6.6; $F(1,118) = 11.61$, $p = .001$), higher resilience (59.0±7.4 *vs*. 54.3±9.1; $F(1,118)=4.22$, $p=.042$), higher self-regulation competences (121.2±14.3 *vs.* 111.8±12.7; $F(1,118) = 5.90$, $p = .017$), and more social support (46.6±7.5 *vs*. 35.3±9.2; $F(1,118) = 38.32$, $p < .001$), when compared with the ones who feel that CC affects PLTF.

[Table 3 near here]

Table 4 shows the results of the unadjusted and adjusted results of the logistic regression analysis across the different psychosocial variables and CC not affecting PSCH/PLTF, including the total group of adolescents.

[Table 4 near here]

In the unadjusted analysis, a higher health-related quality of life was associated with feeling that CC does not affect PSCH (OR 1.11; CI 95% 1.06-1.17, $p<0.001$). Additionally, adolescents perceiving a better psychosomatic health (reporting less symptoms) were more likely to feel that CC does not affect school participation (OR 1.31; CI 95% 1.16-1.47, $p<0.001$); this association is also present for resilience (OR 1.08; CI 95% 1.01-1.15, $p<0.05$), self-regulation (OR 1.08; CI 95% 1.03-1.13, $p<0.01$), and social support (OR 1.14; CI 95% 1.07-1.22, $p<0.001$). The results of the adjusted regression analysis, when all variables were introduced into the model, and after adjusting for age, gender, diagnosis of chronic condition and education level of father and mother, showed that the link between psychosomatic health (OR 1.32; CI 95% 1.12-1.57, $p<0.01$) and not feeling that the CC affects school participation maintained a positive association, though it was slightly less significant ($p<0.001$ *vs*. $p<0.01$). Self-regulation also maintained a positive association, with the same level of significance (OR

1.08; CI 95% 1.02-1.15, $p<0.01$). In turn, health-related quality of life, resilience, and social support were no longer significant for the group of adolescents after the adjustment.

The unadjusted results showed that the group of adolescents who felt that CC does not affect PLTF reported higher levels for all of the psychosocial variables, except for resilience. A higher health-related quality of life was associated with feeling that CC does not affect participation in leisure time with friends (OR 1.10; CI 95% 1.05-1.16, $p<0.001$). Adolescents experiencing a better psychosomatic health (reporting less symptoms) tended to feel that CC does not affect PLTF (OR 1.16; CI 95% 1.05-1.28, $p<0.01$). This is also true for self-regulation (OR 1.07; CI 95% 1.02-1.12, $p<0.01$) and social support (OR 1.26; CI 95% 1.13-1.41, $p<0.001$). The results of the adjusted regression analysis, when all variables were introduced into the model, and after adjusting for age, gender, diagnosis of chronic condition and education level of father and mother, show that the link between social support (OR 1.23; CI 95% 1.08-1.40, $p<0.01$) and the feeling that the CC does not affect PLTF maintained a positive association, even though it was slightly less significant ($p<0.001$ *vs*. $p<0.01$). In turn, all the other psychosocial variables, namely health-related quality of life, symptoms check-list, resilience, and self-regulation were no longer significant for the group of adolescents after the adjustment.

DISCUSSION

The first aim of this study was to identify differences in psychosocial variables between adolescents who feel that CC affects or does not affect PSCH and PLTF. Focusing on the socio demographic and clinical variables, it was found that the majority of the adolescents report that living with a CC does not affect participation at school; neither does it affect the participation in leisure time with friends. This finding is consistent with previous research showing that the majority of adolescents with chronic illness are satisfied with their personal and social lives, while the remaining found the disease challenging [1]. Despite such results, a substantial number of adolescents (13-18%) express that CC affects participation at school and participation in leisure time with friends. It is possible that this group may need more support, compared to their peers, in adapting to the impact of the disease. Statistically significant differences were also found, for all psychosocial variables, between adolescents who felt that CC affects/does not affect PSCH. Adolescents who felt that CC does not affect PSCH showed higher health-related quality of life, better psychosomatic health, higher resilience, higher self-regulation competences, and more social support, when compared to individuals who felt that

CC affects PSCH. The same significant differences were found for all psychosocial variables among adolescents who felt that CC affects/does not affects PLTF. These results match the literature, thereby serving as evidence that the effects of living with a CC in adolescence can be extended to other contexts (e.g., school, and peer relationships), in addition to the individual level [8]. The consequences may be a weakening of the connections between adolescents, other people, and institutions. This weakening could lead to higher risk of decreased participation in educational and social activities [18] . Such results also emphasize studies demonstrating that, in the presence of cumulative risks (e.g., having CC and feeling it affects PSCH/PLTF), the impact on an adolescent's well being [7] and quality of life [6] can be stronger. Therefore, it seems that for healthy psychosocial functioning, the impact of the illness assumes a higher importance than either the diagnosis or the disease severity itself [1,10,29]. Furthermore, in accordance with the literature, and in line with the proposed hypothesis in this study, the group of adolescents which felt that CC affects their participation at school and in leisure time with friends, seems to be more vulnerable to have: psychosocial stress [2], adverse health outcomes, unhealthy psychological development [3,4], and poor general quality of life [10]. Taking into account these results, it may be expected that those adolescents can be at higher risk for poor education outcomes [9,10] and isolation from the peer group [11]. This would place them in a vulnerable setting for unhealthy educational and social development in adulthood [13,15]. Thus, schools may need to make an effort to have a comprehensive, coordinated, and systematic approach, as well as a safe and supportive education environment that can bring important benefits to students (better attendance, fewer symptoms, and fewer restrictions to participation in physical and special activities). This would ensure that they would have the same educational opportunities as their healthy peers. To this end, teachers, parents, students, health care providers, and the community should strive to work together [11].

The second aim of this study focused on assessing the extent to which psychosocial variables were associated with affecting and not affecting both areas of participation. Concerning participation at school, results show that all psychosocial variables presented a significant relationship with the group of adolescents who feel that the CC does not affect school. This group tended to report a higher health-related quality of life, better psychosomatic health, higher resilience, higher self-regulation, and more social support. However, the results show that after controlling for age, gender, diagnosis of chronic condition, and education level

of father/mother, self-regulation and psychosomatic health were the most important psychosocial variables to explain such association. The importance of self-regulation finds support in previous research, suggesting that living and adapting to a CC involves adherence to multiple complex daily tasks, and that all these demands require a high level of self-regulation in order to improve health outcomes [39]. So, as expected, the adolescents who report higher self-regulation concerning their chronic condition are more likely to feel that it does not affect participation at school. Self-regulation can also be, somehow, related to disease management strategies. This is an increasingly important area, defined in the literature, and fundamental to reduce symptoms in most chronic diseases. Although those strategies inspired several health policy makers and innovations in the general health care systems, they are still often focused on medical domains, neglecting the psychosocial needs of young people with chronic health conditions [40]. Therefore, the promotion of self-regulation skills could be a focus of intervention programs for adolescents who feel that CC has an impact on their social participation activities [41]. Psychosomatic health is also considered to be an important variable having an association with adolescents who feel that the disease does not affect participation at school. This is in line with previous research [4], which has demonstrated that psychosomatic complaints cause an enormous burden, representing an additional weight to chronically ill adolescents, along with their basic conditions. To have these harmful health effects in mind is a key aspect of which health professionals, dealing with adolescents, must be aware in order to help to better target the treatment and improve the management of the disease. Still based on research, an additional explanation can be related to the fact that adolescents with less severe medical conditions or treatments, and with better health, express less concerns about the social impact and possible disruption in friendships [17]. Also, they can be at a lower risk of experiencing restrictions than other adolescents [19]. Therefore, adolescents with more difficulties in various psychosocial variables may avoid social situations or activities, which may lead to poorer school attendance or lack of participation in peer-group interactions [9,10,11]. Regarding the participation in leisure time with friends, all psychosocial variables (except resilience) had a significant relationship with the group of adolescents who felt that the CC does not affect participation in leisure time with friends. These adolescents are more likely to experience a higher health-related quality of life, better psychosomatic health, higher self-regulation, and better social support. However, the results show that, after controlling for age, gender, subgroup of chronic condition and education level of father/mother, social support was

the sole and most important variable explaining this association. These results are in accordance with the literature suggesting that social support plays a crucial role (mostly in the presence of a chronic condition) [14,17], that connections with peers are key aspects for healthy youth [15,16], and that participation in social activities can improve quality of life. The inclusion of adolescents' close friends and peer relations in the treatment process, in the disease management (i.e., increase friend's support and recruit them to facilitate health-promoting behaviors), and in school reentry programs, can be important actions to facilitate disease adaptation and to prevent friendships from being disrupted when youngsters miss school due to the illness. These issues can also be addressed by health care providers within the medical setting, as has been proposed in previous research [17]. In addition, evidence-based research is suggesting new ideas to improve outcomes for people with chronic conditions, such as face-to-face peer support, either using school-based and disease-specific programs, or community-based and generic ones, as well as internet-based support and other technologically-mediated methods [2].

The third aim of this study was to identify the most relevant and amenable psychosocial variables to intervention, which could help to maximize social participation of adolescents with CC. In spite of the previous explained results, it is often difficult to determine if psychosocial functioning problems are due to underlying illness, the treatment, or to the consequences of either illness or treatment. Also, better social participation is correlated with more self-efficacy and independence, and not necessarily with higher health-related quality of life and *vice-versa*. Thus, improved knowledge on social participation and on psychosocial variables may give a clear rationale, for the implementation of more appropriate protocols and interventions, in order to increase social skills and social support, to improve behavioral/emotional health, to eliminate barriers, and to maximize successful participation [10,19].

In face of this evidence, rather than adopting a standardized approach, it is crucial to address all of the important psychosocial areas [20-25] in the specific age group of adolescents [27,28] and in their life contexts. What must be applied is an integral perspective that represents the holistic care of these adolescents [11,20]. Such suggestions are in line with the adolescent-friendly health services concept, developed by the World Health Organization –WHO, which includes a physical, psychological, and social perspective.

This study has some limitations. The sample used was not representative. Plausible generalizations should take this into consideration. Self-reported data might introduce recall bias, and due to the heterogeneity of the group of adolescents (different diseases/limitations), some are likely to be underrepresented. The cross-sectional design of the study precludes inferences concerning causality, offering a weak basis to examine the direction of the effects. Longitudinal data would be needed. Nevertheless, this study has numerous strengths, such as the innovation of the focus on improving knowledge of connectedness and psychosocial variables in the specific period of adolescence. Other strengths include the use of self-reported information from the adolescent's themselves and not through parents proxys, and well-validated measures for health-related quality, psychosomatic health, resilience, and social support assessment. It would be important to replicate these variables in a larger sample, and in specific populations, in forthcoming research.

Conclusions

The present study highlighted the association between the impact of living with a chronic condition and school and peers connectedness, and the relationship between several key psychosocial factors that have not often been evaluated. There are a few implications. Considering that adaptation responses can be quite varied, and well being can go beyond mere medical aspects (diagnosis/severity), it might be worthwhile for clinicians to turn their attention to the assessment of the impact of a chronic condition on adolescents' lives and contexts. This suggestion is valid because it has been underlined that there are a substantial number of adolescents who feel that the disease affects their PSCH and PLTF; they seem to be at a higher risk in their psychosocial well being. Once these vulnerable adolescents are identified, interventions, which focus on providing support and opportunities for healthy youth development, can be implemented. Ultimately, what is needed is a complex and multifactorial approach that includes clinicians, schools, family, and peers.

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Table VIII-7-1. Psychosocial variables

Name	Psychosocial Measure	Abbreviation (in this study)	Short Description
KIDSCREEN-10 Index[34]	Health-related quality of life – HRQoL	KIDS-10	• Short version of KIDSCREEN-52; • Used in the HBSC/WHO Study[32] • 10 items, on a 5-point Likert-type scale; • Ranges from 0 to 100; • Lower values reflect feelings of unhappiness, dissatisfaction and inadequacy. Higher values reveal feelings of happiness, perception of adequacy and satisfaction with the adolescent's life contexts. • α = .83
Symptoms Check List (SCL-HBSC)[35]	Psychosomatic complaints (unidimensional latent trait).	SCL	• Used in the HBSC/WHO Study[32] • 8 items focusing on subjective physical and psychological health complaints; • Each item answered on a 5-point Likert-type response scale; • Resultant values between 1 (worst health) and 5 (best health); • Ranges from 8 to 40. • α = .78
Healthy Kids Resilience Assessment Module[36]	Resilience (2 dimensions: external and internal resources).	RES	• The present study only considered the internal resources dimension; • 18 items answered on a 4-point scale; • Ranges from 18 to 72; • Higher scores indicate higher levels of competences, protection and resilience to adversity. • α = .0.72
Adolescent Self-Regulatory Inventory – ASRI[37]	Self-regulation (2 dimensions: Short term-SR-ST and Long term-SR-LT).	SR	• In this study the instrument was translated from the original English version into Portuguese language. It was then revised by a group of specialized experts within this field and a pre-test with a group of students was conducted in schools. • 36 items answered on a 5-point Likert scale; • Ranges from 36 to 180. • Higher values indicate better competences of self-regulation. • α = .0.79
Scale of Satisfaction with Social Support[38]	Satisfaction with social support (2 dimensions: Satisfaction with Social Support-SSS; and Need for Activities connected to Social Support-NASS).	SSSS	• Translation and adaptation for children and adolescents of a Satisfaction with Social Support Scale for adults; • 12 items answered on a 5-point scale; • Ranges from 18 to 72; • Higher scores indicate higher satisfaction with social support (SSS) or higher satisfaction for not feeling the need to have more social support activities (NASS). • α = .85

Table VIII-7-2. Socio-demographic and clinical characteristics for the total group of adolescents with chronic condition

	Total Group N=135
Age (years) (M±SD)	14.0±1.5
Chronic Condition diagnosis (%)	
Diabetes	31.9
Allergic Diseases	46.7
Neurologic Diseases	21.5
Gender (%)	
Boy	51.9
Girl	48.1
Education Level - Father (%)	
Basic Level (1st-9th Grades)	64.6
Secondary Level (10th-12th Grades)	23.6
Superior (or more) Level (University, Post-Graduate)	11.8
Education Level - Mother (%)	
Basic Level (1st-9th Grades)	53.8
Secondary Level (10th-12th Grades)	29.5
Superior (or more) Level (University, Post-Graduate)	16.7
"Does your long-term illness, disability or medical condition affects your attendance and participation at school?" (%) - PSCH	
No	82.2
Yes	17.8
"Does your long-term illness, disability or medical condition affects your attendance and participation in leisure activities with friends, classmates?" (%) - PLTF	
No	86.7
Yes	13.3

Table VIII-7-3. Comparison of psychosocial study variables according to chronic condition affecting/not affecting participation at school (PSCH) and affecting/not affecting participation in leisure time with friends (PLTF)

	ADOLESCENTS WITH CC (M±SD)						
	Total	**Not affects PSCH**	**Affects PSCH**	***p***	**Not affects PLTF**	**Affects PLTF**	***P***
KIDS-10	79.7±12.5	82.2±10.1	68.0±15.6	<0.001	81.6±10.6	67.3±16.6	<0.001
SCL	35.6±4.8	36.7±3.8	30.3±5.8	<0.001	36.2±4.2	31.6±6.6	0.001
RES	58.4±7.8	59.0±7.4	55.5±9.1	0.015	59.0±7.4	54.3±9.1	0.042
SR	120.0±14.4	121.8±14.4	110.9±10.6	0.001	121.2±14.3	111.8±12.7	0.017
SR-S	41.8±6.8	42.7±6.7	37.6±5.7	0.001	42.4±6.7	37.9±5.9	0.011
SR-LT	50.2±7.7	51.1±7.7	46.2±6.1	0.013	50.7±7.7	46.8±7.0	0.061
SSSS	45.1±8.6	46.6±7.6	38.2±10.0	<0.001	46.6±7.5	35.3±9.2	<0.001
NASS	15.8±4.7	16.5±4.4	12.6±4.4	0.001	16.4±4.3	12.0±4.9	<0.001
SSS	29.1±5.4	30.0±4.3	25.3±7.6	<0.001	30.03±4.3	23.3±7.7	<0.001

***p< .001; **p< .01; *p< .05
Tested by GLM – Univariate ANCOVA.
Analyses were adjusted for age, gender, diagnosis of chronic condition and educational level – father and mother.
CC – Chronic Condition; PSCH – Participation at School; PLTF – Participation in Leisure Time with Friends; SCL – Symptoms Check List; KIDS – KIDSCREEN; RES – Resilience; SR – Self-regulation; SR-ST – Self-regulation short term; SR-LT – Self-regulation long term; SSSS – Social Support; NASS – Need for Activities connected to social support; SSS – Satisfaction with social support.

Table VIII-7-4. Logistic regression analyses with odds ratios (OR) and 95% confidence intervals (CI) considering the group of adolescents with CC not affecting PSCH and PLTF, and psychosocial study variables, on a sample of adolescents with chronic conditions (N=135) from Lisbon, carried out in 2013.

	CC Does not affects PSCH		**CC Does not affects PLTF**	
	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
KIDS-10	1.11 (1.06-1.17)***	1.04 (0.96-1.13)	1.10 (1.05-1.16)***	1.03 (0.93-1.14)
SCL	1.31 (1.16-1.47)***	1.32 (1.12-1.57)**	1.16 (1.05-1.28)**	1.02 (0.86-1.21)
RES	1.08 (1.01-1.15)*	0.91 (0.82-1.02)	1.07 (1.00-1.15)	0.94 (0.82-1.07)
SR	1.08 (1.03-1.13)**	1.08 (1.02-1.15)**	1.07 (1.02-1.12)**	1.05 (0.97-1.12)
SSSS	1.14 (1.07-1.22)***	1.06 (0.96-1.17)	1.26 (1.13-1.41)***	1.23 (1.08-1.40)**

***p< .001; **p< .01; *p< .05

Analysis were adjusted for age, gender, diagnosis of chronic condition and educational level – father and mother.

CC – Chronic Condition; PSCH – Participation at School; PLTF – Participation in Leisure Time with Friends; KIDS – KIDSCREEN; SCL – Symptoms Check List; RES – Resilience; SR – Self-regulation; SSSS – Social Support.

Chapter VIII

Research Phase III – Empirical Studies 6-9

Empirical Study 8

Gender Differences in Health-related Quality Of Life of Adolescents with a Chronic Disease in a Clinical Context

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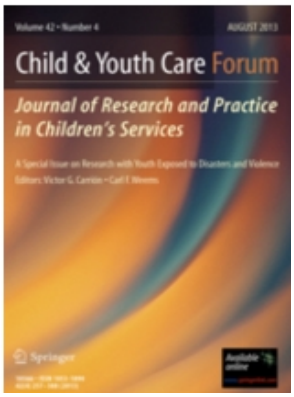

ABSTRACT

Background: Living with a chronic disease in adolescence can affect psychosocial functioning, Quality of Life (QoL) and Health-related Quality of Life (HRQoL); and girls traditionally report a heavy burden and worse outcomes, when compared to boys.

Objective: This study aims at analyzing the impact of a chronic disease in HRQoL's dimensions and in psychosocial variables, considering gender differences on such association.

Methods: A cross-sectional study was conducted in a clinical population of 135 adolescents with chronic diseases (51.9% boys; 48.1% girls), average age: 14±1.5 years old. Socio-demographic/clinical variables, HRQoL (KIDSCREEN-52) and psychosocial variables (Psychosomatic Health, Resilience, Self-regulation and Social Support) were assessed.

Results: Girls reported worse outcomes in most of HRQoL's dimensions and in Psychosomatic Health, compared to boys. Controlling for school/social participation, HRQoL was impacted in a different way: a safe and social environment was essential to girls, whereas boys were more in need to promote personal competencies (self-regulation, control of symptoms and resilience).

Conclusions: This study highlights the gendered impact of a chronic disease in HRQoL's dimensions and in psychosocial variables in adolescents, indicating that girls and boys have different needs. It suggests that HRQoL and protective factors should be implemented in psychosocial care, and the assessment of HRQoL and psychosocial variables would need to be routinely assessed in a paediatric context, within a gendered framework and taking into account limitations in ordinary activities. The identification of specifically impaired HRQoL's domains allows professionals to better plan effective and multifactorial psychosocial interventions.

Keywords: Adolescents; Chronic Diseases; Gender; Health-related Quality of Life; KIDSCREEN-52; Psychosocial Functioning.

INTRODUCTION

In the last decades, chronic diseases in adolescence have been rapidly increasing, due to the efforts and advances in medicine and also to the decrease in mortality rate during infancy (Sattoe et al., 2015). Adolescence is a period of profound bio and psychosocial changes, and living with a chronic disease in this phase can bring out additional challenges, represent a major psychosocial burden (Sawyer, Drew, Yeo, & Britto, 2007), increasing the vulnerability for adverse health outcomes and psychological development (Santos, Matos, Simões, & Machado, 2015; Suris, Bélanger, Ambresin, Chabloz, & Michaud, 2011). Thus, these adolescents may feel impaired in their general quality of life (QoL) (Kourkoutas, Georgiadi, & Plexousakis, 2010; Payot & Barrington, 2011) and health-related quality of life (HRQoL) (Petersen-Ewert, Erhart, & Ravens-Sieberer, 2011; Varni, Limbers, & Burwinkle, 2007), in the specific physical, cognitive, social and emotional dimensions (Compas, Jaser, Dunn, & Rodriguez, 2012; Verhoof, Maurice-Stam, Heymans, & Grootenhuis, 2012).

HRQoL is a multidimensional construct including the psychological, mental, social and spiritual domains, as well as functional aspects of wellbeing (Ravens-Sieberer et al., 2001; 2005). It has assuming a major concern among health professionals (Koot, 2002), due to its possible impact on the well-being, healthy development and health outcomes (de Ridder, Geenen, Kuijer, Van Middendorp, 2008). The perceptions of adolescents regarding their HRQoL can be influenced by different factors such as gender, age, personal/family characteristics and socio-economic status (Gaspar, Ribeiro, Matos, Leal, & Ferreira, 2012; The KIDSCREEN Group Europe, 2006; Ravens-Sieberer et al., 2001; 2005). Furthermore, individual perceptions and adaptation towards the disease can be a changeable process and moderated by gender (Holden, Chmielewski, Nelson, & Kager, 1997). In chronically ill adolescents, the literature underlined a tendency for girls, when compared to boys, to report poorer health outcomes (Määttä et al., 2013), and higher risk in various domains, namely in quality of life and disease-related worries (Zashikhina & Hagglof, 2014), psychological symptoms (Santos Matos, Simões, Fonseca, & Machado, 2013; Suris, Parera & Puig, 1996; Williams, Sharpe & Mullan, 2013) and life satisfaction (Santos et al., 2013). However, in social dimensions, girls report higher peer relationship quality (Rassart et al., 2012), physical/social HRQoL's dimensions (Alba et al., 2013) and less externalizing problems (Carona, Moreira, Silva, Crespo, & Canavarro, 2014) than boys. In general population and in Portuguese studies, these gender differences follow the same direction (Currie et al., 2012; Gaspar, Matos, Ribeiro,

Leal, & Albergaria, 2014; Marcotte, Fortin, Potvin & Papillon, 2002; Matos, 2000-2014; Piko, 2006) and different internalization/externalization patterns as well as gender-specific puberty experiences can play an important role to explain such findings (Cavallo et al., 2006).

In addition, the adaptation responses to the disease rely on the dynamic relationship between the adolescent, his environment (Houtrow, Jones, Ghandour, Strickland, & Newacheck, 2012), and psychosocial variables (Denny et al., 2014; Mackner, Bickmeier, & Crandall, 2012). Therefore, regarding psychosocial variables and grounding in The Asset Model (Morgan & Ziglio, 2007) it is important to pay attention to protective factors underlined in the literature with chronically ill adolescents, that can predict positive health outcomes and improve coping skills (Maslow & Chung, 2013), such as psychosomatic health (Suris et al., 2011), resilience (Helgeson, Reynolds, Siminerio, Becker, & Escobar, 2014; Hilliard, Harris, & Weissberg-Benchell, 2012; Matos et al., 2012; Payot & Barrington, 2011), self-regulation (Gois et al., 2012) and social support (Békési et al., 2011; Wu, Geldhof, Roberts, Parikshak, & Amylon, 2013). Accordingly, to study the consequences of the disease and for the holistic care of these adolescents it is needed an evaluation focusing less on diagnostic categories (where more variability exists) and more on the limitations in ordinary activities and on social and emotional health (Denny et al., 2014; van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007). Thus, suggesting the need to assess psychosocial dimensions (psychological and social perspectives) (Pulkki-Råback, 2015; Watson, 2014; Suris, Michaud, & Viner, 2004; Gaspar et al., 2012), which have become increasingly recognized and acknowledged in clinical settings, as complementary to traditional health indicators (Health, 2013; Marmot et al., 2012; Pulkki-Råback et al., 2014; Watson, 2014). Therefore, this is an important and relevant area of research for educators and clinicians, both in primary care and specialties.

Facing this scenario, the present study aimed to: 1) identify the impact of living with a chronic disease in adolescence, in the several dimensions of HRQoL and in key complementary psychosocial variables (psychosomatic complaints, resilience, self-regulation and social support); and 2) assess the extent to which psychosocial variables were associated with the several dimensions of HRQoL, analyzing gender differences moderating those associations. These objectives are in line with previous research suggesting the need to address more the impact of chronic diseases on emotional health and socialization processes (Denny et al., 2014),

tailoring for gender different needs, in order to promote a better social adjustment and disease management (La Greca, Bearman, & Moore, 2002).

METHODS

Participants, Design and Procedure

This cross-sectional study included 135 adolescents with a diagnosis of chronic disease (diabetes, allergic diseases or neurologic diseases), mainly boys (*n*=70), with a mean age of 14±1.5 years old and attending the pediatric outpatient department of a public central hospital. The choice of these chronic clinical situations was based on the evidence that asthma, epilepsy, and diabetes are some of the most prevalent chronic diseases in adolescence (Barros, 2009). Most of these adolescents had Portuguese nationality (*n*=132), lived in Lisbon (*n*=114), attended the 7-9th school grades (*n*=72). They also had 7.5±4.7 years of median time of diagnosis, generally did not use special equipment due to the disease (*n*=83) and mostly took disease-related medication (*n*=88).

An ethical approval for this study was obtained from The Ethics Committee for Health from CHLN-EPE, the institution's ethical committees (Compliance with Ethical Standards: Reference PCA-12 Nov.2012-0785), before the data collection. Adolescents and their parents were selected and then approached directly by their health professionals (physicians and/or nurses), who helped to identify the following applied criteria for inclusion: 1) diagnosis of chronic disease established by a physician (in the specific medical expertise appointments: neurology, allergic diseases, and endocrinology) and also ascertained in the questionnaire; 2) ages including both groups of young teens (12-14Y) and teenagers (15-17Y), according to the definition of age ranges of the Centers for Disease Control and Prevention – CDC, and 3) to have the cognitive skills necessary to fill out the questionnaire autonomously. Detailed information about the study aims and procedures was provided to all participants, in accordance with the World Medical Association Declaration of Helsinki's guidelines (WMA, 2008). The participation was voluntary and the agreement and informed consent required by the ethical committee was filled, by both adolescents and their parents. Data were collected (whenever possible in an individual medical office) using a self-report questionnaire either after or before the medical appointment, according to the most opportune moment. Research assistance was available to provide support whenever necessary.

Measures

Self-report questionnaires were used to assess socio-demographic, clinical and psychosocial variables. Socio-demographic consisted of age, gender, geographic region, nationality and education level (adolescents and parents). Clinical variables comprised: 1) time since diagnosis, 2) the use of special equipment related to the disease, 3) the item "Does your long-term illness, disability or medical condition affect your attendance and participation in leisure activities with friends, classmates? No/Yes" (PLTF), 4) medication intake related to the disease; and, 5) the item "Does your long-term illness, disability or medical condition affect your attendance and participation at school? No/Yes" (PSCH). Items 3, 4 and 5 are included in the international study Health Behaviour in School-aged Children (HBSC/WHO) (Matos & Equipa Aventura Social, 2000-2014; Roberts et al., 2009), and items 4 and 5 constitute The Chronic Condition Short Questionnaire (CCSQ) (Mazur et al., 2013), an optional package for Chronic Conditions within HBSC/WHO. These centered items on the disease's consequences (missing school classes, medication), allow to assess the effect of the disease on adolescents' activities and enlighten its psychosocial impact, presenting considerable strengths over a single, open-ended item. Co-existing problems related to disease, such as medication intake, and/or missing school classes are reported as good indicators of severity (Mazur et al., 2013), therefore, these items together were regarded as a proxy for disease's severity.

The psychosocial variables included HRQoL (KIDS-52) and complementary scales, such as: Psychosomatic Health Complaints (SCL), Resilience - Scale Healthy Kids Resilience Assessment Module (RES), Self-regulation - Scale Adolescent Self-Regulatory Inventory – ASRI (SR), and Social Support - Scale of Satisfaction with Social Support (SSSS). These instruments are presented in more detail in Table 1.

[Table 1 near here]

Statistical Analysis

Descriptive statistics were calculated for both demographic, clinic, and psychosocial variables (means, standard deviation, and percentages) for the total group of adolescents. All data were tested for normality prior to any analyzes using Shapiro-Wilk and Kolmogorov-Smirnov tests, as well as Levene's test for the homogeneity of the variance. An independent t-test was conducted to determine differences between boys and girls with chronic disease for the

HRQoL and the complementary psychosocial scales. Later, linear regression models were used to assess the extent to which the complementary psychosocial scales were associated with the HRQoL's several dimensions, controlling for "affecting/not affecting school participation" (PSCH) and "affecting/not affecting leisure time with friends" (PLTF), in the total sample and running separate analysis by gender. All statistical analyzes were completed using IBM Statistical Package for Social Sciences (SPSS), version 22.0. The significance level was set at $p<0.05$.

RESULTS

The included socio-demographic and clinical variables for the total group of adolescents are presented in Table 2.

[Table 2 near here]

The differences between gender for the total group of adolescents with CC, considering the total dimensions of KIDSCREEN-52 and the complementary psychosocial variables are presented in Table 3. The results show that in the present study girls had statistically significantly lower values when compared to boys, for the majority of the following HRQoL's dimensions: PHY-Physical well-being (66.2±15.0 *vs*. 72.6±17.6, $t(133)=2.251$, $p=0.026$); PBW-Psychological well-being (79.6±14.6 *vs*. 85.3±13.1, $t(133)=2.386$, $p=0.018$); EMO-Mood & Emotions (79.0±15.7 *vs*. 84.9±14.9, $t(133)=2.245$, $p=0.026$); SEL-Self-perception (75.5±16.1 *vs*. 81.7±14.4, $t(133)=2.366$, $p=0.019$); AUT-Autonomy (73.3±29.9 *vs*. 87.3±13.3, $t(133)=4.690$, $p=0.001$); PAR-Parent relation & Home life (82.1±15.1 *vs*. 88.1±13.4, $t(133)=2.461$, $p=0.015$); and finally FIN-Financial Resources (79.6±21.1 *vs*. 86.7±17.1, $t(133)=2.147$, $p=0.034$). No significant differences were found regarding the dimensions SOC-Social Support & Peers, SCH-School Environment and BUL-Social Acceptance & Bullying. With respect to the complementary psychosocial variables, girls presented significantly worse psychosomatic health (reporting more physical and psychological symptoms) in the SCL, when compared to boys (34.5±5.0 *vs*. 36.6±4.5, $t(133)=2.523$, $p=0.013$). No significant differences were found for RES, SR and SSSS.

[Table 3 near here]

In a second step, controlling for the impact of the chronic disease in the participation at school (PSCH) and in leisure time with friends (PLTF), a linear regression analysis was conducted considering the impact of the complementary psychosocial variables on the several dimensions of health-related quality of life (for the total sample and by gender). Such results are presented in Table 4.

[Table 4 near here]

Psychosomatic Health Complaints (SCL-Symptoms Check-List)

SCL significantly impacted the dimension PHY of HRQoL, for the total group of adolescents [$F(7,127)=9.158$, $p<0.001$, $R^2=.299$], and for both boys and girls considered separately [$F(6,63)=5.062$, $p<0.001$, $R^2=.261$]; [$F(6,58)=5.932$, $p<0.001$, $R^2=.316$]. The same significantly association was observed for the dimension EMO, for the total group of adolescents [$F(7,127)=23.113$, $p<0.001$, $R^2=.536$], and for both boys and girls [$F(6,63)=14.753$, $p<0.001$, $R^2=.545$]; [$F(6,58)=10.948$, $p<0.001$, $R^2=.483$].

Furthermore it impacted significantly the dimension PBW for the total sample [$F(7,127)=22.026$, $p<0.001$, $R^2=.523$], but only for boys [$F(6,63)=12.923$, $p<0.001$, $R^2=.509$]. The dimension PAR also had a significantly association, but only for the total sample [$F(7,127)=15.146$, $p<0.001$, $R^2=.425$] and no gender differences were found.

Resilience (RES)

RES significantly impacted the dimension PBW of HRQoL, for the total group of adolescents [$F(7,127)=22.026$, $p<0.001$, $R^2=.523$], but only for boys [$F(6,63)=12.923$, $p<0.001$, $R^2=.509$]. It impacted in the same direction the dimension PAR for the total sample [$F(7,127)=15.146$, $p<0.001$, $R^2=.425$] and for boys [$F(6,63)=10.969$, $p<0.001$, $R^2=.464$]. The same association was found for the dimension SOC in the total sample [$F(7,127)=10.967$, $p<0.001$, $R^2=.342$], and for boys [$F(6,63)=4.288$, $p=0.001$, $R^2=.222$].

Moreover it impacted the dimension AUT only in the boys sub-group [$F(6,63)=5.319$, $p<0.001$, $R^2=.273$], and no differences for the total sample were shown.

Self-regulation (SR)

SR had a significantly association with the HRQoL dimension SCH in the total sample [$F(7,127)=7.971$, $p<0.001$, $R^2=.267$], but only for boys [$F(6,63)=4.716$, $p=0.001$, $R^2=.244$]. It also impacted the dimension PHY but only for girls [$F(6,58)=5.932$, $p<0.001$, $R^2=.316$].

Satisfaction with Social Support (SSSS)

SSSS impacted the dimension PBW of HRQoL, for the total group of adolescents [$F(7,127)=22.026$, $p<0.001$, $R^2=.523$], both for boys and girls considered separately [$F(6,63)=12.923$, $p<0.001$, $R^2=.509$]; [$F(6,58)=12.900$, $p<0.001$, $R^2=.527$]. The same significantly association was observed for the dimension EMO, for the total group of adolescents [$F(7,127)=23.113$, $p<0.001$, $R^2=.536$], and for boys and girls [$F(6,63)=14.753$, $p<0.001$, $R^2=.545$]; [$F(6,58)=10.948$, $p<0.001$, $R^2=.48.3$]. SSSS additionally impacted the dimension SEL for the total sample [$F(7,127)=10.991$, $p<0.001$, $R^2=.343$], in boys and girls [$F(6,63)=7.627$, $p<0.001$, $R^2=.421$]; [$F(6,58)=4.509$, $p=0.001$, $R^2=.248$], and, the dimension PAR for the total group [$F(7,127)=15.146$, $p<0.001$, $R^2=.425$], and for boys and girls [$F(6,63)=10.969$, $p<0.001$, $R^2=.464$]; [$F(6,58)=6.012$, $p<0.001$, $R^2=.320$].

Moreover, a significantly association was found for the total sample in the dimensions AUT [$F(7,127)=17.704$, $p<0.001$, $R^2=.466$], and SOC [$F(7,127)=10.967$, $p<0.001$, $R^2=.342$], but respectively only in the girls group [$F(6,58)=11.935$, $p<0.001$, $R^2=.506$]; [$F(6,58)=13.875$, $p<0.001$ $R^2=.547$]. The dimension FIN had a significantly impact as well, but only for the total group of adolescents [$F(7,127)=8.901$, $p<0.001$, $R^2=.292$].

DISCUSSION

The present findings suggests that living with a chronic disease in adolescence can impair general HRQoL, as expected and in line with the literature (Compas et al., 2012; Kourkoutas et al., 2010; Payot & Barrington, 2011; Petersen-Ewert et al., 2011; Varni et al., 2007; Verhoof, et al., 2012). Moreover, the present results points out that gender has a significant role for outcomes in the various dimensions of HRQoL, as well as in complementary psychosocial variables, reinforcing previous research (Holden, 2007; Gaspar et al., 2012; The KIDSCREEN Group Europe, 2006; Ravens-Sieberer et al., 2001, 2005).

Specifically regarding gender differences, girls surface a poorer perception of HRQoL when compared to boys, presenting lower scores for the following dimensions: PHY, PBW,

EMO, SEL, AUT, PAR and FIN. Nevertheless, there was no significant results for the dimension SOC, SCH and BUL. Considering the complementary psychosocial variables, significant gender differences in the SCL was also reported, and girls once more present worse results. No significant gender differences were found for RES, SR, and SSSS. The findings surfacing poorer outcomes for girls when compared to boys, are in line with previous research, both in chronically ill adolescents (Määttä et al., 2013; Suris et al., 1996; Williams et al., 2013; Santos et al., 2013; Zashikhina & Hagglof, 2014) and also in general population (Currie et al., 2012; Gaspar et al., 2014; Marcotte et al., 2002; Matos, 2000-2014; Piko, 2006).

Interestingly, in the second step of the conducted linear regression, when controlling for "chronic condition affects/not affects participation at school" (PSCH), and "chronic conditions affects/not affects participation in leisure time with friends" (PLFT), the perception of HRQoL was impacted in a different way by gender. Although girls in general, are still more affected by a poor HRQoL, the interesting feature is that significantly differences are revealed only for the boys' subgroup, such as: SCL impacted the dimension PBW, and SR impacted SCH. In the same direction of association, RES had a significant impact on the dimensions PBW-Psychological Well-being, AUT-Autonomy, PAR-Parent Relation & Home Life and SOC-Social Support & Peers. Therefore, it seems that boys may benefit from interventions aiming to develop and increase personal competencies, such as self-regulation, symptom's control and mostly resilience, which are precisely reported in the literature as relevant domains to promote a better adaptation to the disease and promote HRQoL (Békési et al., 2011; Gois et al., 2012; Hilliard et al., 2012; Helgeson et al., 2014; Matos et al., 2012; Payot & Barrington, 2011; Suris et al., 2011; Wu et al., 2013). Specifically, it may be suggested to increase the levels of self-management in disease-related tasks (Chao, Whittemore, Minges, Murphy, & Grey, 2014). Also to better help to identify the irreversible aspects of the chronic disease, allowing the adolescents' resilience and adaptation to deal with the new reality, seems to improve well-being and HrQoL. This appears to be a universal psychological response to adversity foreseeing that adaptation to a chronic disease requires a certain degree of acceptance (Payot & Barrington, 2011). Thus, resilience frequently allows adaptation to adverse health states conducting to better outcomes in HRQoL, but it has been observed that while facing challenges, some youth struggle, while others do not. To learn practical and clinically relevant strategies from resilient adolescents can better help planning psychosocial care for those that struggle (Hilliard et al.,

2012), and resilience seems to be a promising candidate for interventions designed to reduce stress and improve outcomes (Guilera, Pereda, Paños, & Abad, 2015; Helgeson et al., 2014; Yi-Frazier et al., 2013).

Furthermore, only for the girls' subgroup, when controlling for PSCH and PLTF, significance was also shown on two psychosocial variables. Self-regulation (SR) impacted the dimension PHY-Physical Well-Being, and, overall, from the considered study psychosocial variables, Satisfaction with Social Support (SSSS) seemed to be the most significant one, indicating a different and higher role for social support than observed before (Table 3). This was particularly true considering the dimensions AUT-Autonomy and SOC-Social Support & Peers. This findings are in line with evidence reported in the literature, showing that girls have high levels of social support, peer relationship quality, social functioning, less externalizing problems (Alba et al., 2013; Carona, 2014; Rassart et al., 2012), easily share feelings and seek support with peers and family. On the other hand, boys tend to have more externalizing behaviours and adopt compensation ones, reacting as if the problem did not exist. Thus, social support can be considered as a strategic variable that can contribute to a good adaptation while facing potentially stressful new situations, because increases control and reduces tension (Gaspar et al., 2012).

Facing such findings reinforce that complementary psychosocial variables, namely psychosomatic complaints, self-regulation, social support and resilience, impact in a gendered way, several dimensions of HRQoL and might play an important role in the adaptation to adverse health states, leading to a more acceptable quality of life. Thus, supporting the suggestion in the literature that acknowledge psychosocial domains as crucial (Denny et al., 2014; Pulkki-Råback, 2015; Watson, 2014; Suris et al., 2004) to complement traditional health indicators (Health, 2013; Marmot et al., 2012), and drawing attention to potential protective factors for health outcomes (Maslow & Chung, 2013; Morgan & Ziglio, 2007). In spite of this preliminary results in a rather small clinical sample, the present study strongly suggest that in a population of adolescents living with a chronic disease and controlling for school and social participation, girls are more affected by a safe and positive social environment, whereas boys are more in need of interventions that could help developing personal competencies, such as resilience internal assets, self-regulation and symptom's control. Therefore, the several dimensions of HRQoL Life and complementary psychosocial variables need to be routinely monitored in adolescents with chronic conditions, taking into account diverse individual, and

social dimensions (Gaspar et al., 2012; Suris et al., 2004), with a particularly focus on a gendered approach. To identify specific impaired domains can help healthcare professionals to implement multidisciplinary interventions for individualized psychosocial support (Elsenbruch, Schmid, Lutz, Geers, & Schara, 2013).

Limitations and Strengths

This study has some limitations. The sample was not representative and plausible generalizations should take this into consideration. Self-reported data might introduce recall bias, and due to the heterogeneity of the group of adolescents (different diseases/limitations), some are likely to be underrepresented. The cross-sectional design of the study precludes inferences concerning causality, offering a weak basis to examine the direction of the effects. Longitudinal data would be needed. Nevertheless, this study has numerous strengths allowing the increase of knowledge on the impact of a health disease in the several dimensions of HRQoL, and in psychosocial variables, taking gender in consideration. It includes self-reported information from the adolescents and not through parent's proxies, and well-developmentally appropriate measures for health-related quality, psychosomatic health, resilience, and social support assessment. It would be important to replicate this study in a larger sample, and in specific populations, in forthcoming research.

Conclusions

The present study shows that in a clinical sample of adolescents living with a chronic disease, gender has a significant role in the perception of HRQoL's dimensions and in complementary psychosocial variables. Limitations in ordinary activities of these adolescents (school - PSCH and friends – PLTF) also need to be taken into account, once may modify gender impact in a different way. Girls and boys seem to have different needs and a major emphasis to include protective factors in psychosocial care should be implemented, namely social support and personal competencies, such as self-regulation, symptom's control and mostly resilience.

Facing this results, it is highlighted the importance of routinely assess the several dimensions of HRQoL and psychosocial variables in pediatric contexts within a gendered framework. In addition, it is underlined that identifying the specific impaired domains allows

professionals to better plan effective and multifactorial interventions, in order to meet differential health needs of the adolescents living with a chronic disease.

LIST OF ABBREVIATIONS

AUT – Autonomy; SCL – Symptoms Check-List; BUL – Social Acceptance & Bullying; EMO – Mood & Emotions; FIN – Financial Resources; PAR – Parent relation & Home life; PBW – Psychological well-being; PHY – Physical well-being; SCH – School Environment; SEL – Self-perception; SOC – Social Support & Peers; SR – Self-regulation; SSSS - Satisfaction with Social Support; RES – Resilience.

Author's contributions

TS and MGM conceived the study, participated in its design and coordination, draft and authored the manuscript. AM helped to perform statistical analyses, participated in interpretation of data and helped to draft manuscript revisions. CS and TG participated in the study design, interpretation of the data, and helped to draft manuscript revisions. IL and MCM participated in the study design and helped to draft manuscript revisions. All authors have read and approved the final manuscript.

Competing interests

None of the authors reported any financial interests or potential conflicts of interest.

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Ethical approval

This study was conducted in agreement with the Ethical principles of psychologists and code of conduct of the American Psychological Association (APA) in 1992 and the Order of Portuguese Psychologists (OPP), as well as with the ethical principles regarding research with human participants of the World Medical Association Declaration of Helsinki's guidelines in 1964, and its later amendments or comparable ethical standards. In addition, all procedures in the present study were performed in accordance with the ethical standards of the institutional and/or national research appropriate committee (The Ethics Committee for Health from CHLN-EPE, Reference PCA-12 Nov.2012-0785), and written

informed consent was obtained from all individual participants included in the study (both adolescents and their parents/legal guardians). For this type of study, formal consent from adolescents under 14 years old was not required.

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Table VIII-8-1. Psychosocial Variables

Name	Psychosocial Measure	Short Description
KIDSCREEN-52 (KIDS-52) (Gaspar & Matos, 2008; Gaspar et al., 2012; Ravens-Sieberer et al., 2001, 2005, 2008[a]).	Health-related quality of life – HRQoL	• Self-response questionnaire that assesses health issues and chronic illness for ages 08-18 years old; • Includes ten dimensions describing quality of life related with health; • Lower values reflect feelings of unhappiness, dissatisfaction and inadequacy. Higher values show feelings of happiness, perception of adequacy and satisfaction within adolescent's life contexts. • Dimensions (on a 5-point Likert-type scale): - (1) PHY-Physical Well-being (5 items) α = .77; - (2) PBW-Psychological Well-being (6 items) α = .84; - (3) EMO-Mood and Emotions (7 items) α = .86; - (4) SEL-Self-perception (5 items) α = .60; - (5) AUT-Autonomy (5 items) α = .81; - (6) PAR-Parent Relation & Home Life (6 items) α = .84; - (7) FIN-Financial Resources (3 items) α = .88; - (8) SOC-Social Support and Peers (6 items) α = .84; - (9) SCH-School Environment (6 items) α = .84; - (10) BUL-Bullying (3 items) α = .75
Symptoms Check List (SCL) (Ravens-Sieberer et al., 2008[b]; Ravens-Sieberer et al., 2009).	Psychosomatic health complaints (unidimensional latent trait)	• Used in the HBSC/WHO Study (Currie et al., 2001; Roberts et al., 2009). • 8 items focusing on subjective physical and psychological health complaints; • Each item answered on a 5-point Likert-type response scale; • Resulting values between 1 (worst health) and 5 (best health); • Ranges from 8 to 40. • α = .78
Healthy Kids Resilience Assessment Module (RES) (Austin, Bates & Duerr, 2013; Martins, 2005).	Resilience 2 dimensions: - external resources; - internal resources.	• The present study only used the internal resources; • 18 items answered on a 4-point scale; • Ranges from 18 to 72; • Higher scores indicate higher levels of competences, protection and resilience to adversity. • α = .0.72[1]
Adolescent Self-Regulatory Inventory – ASRI (SR) (Moilanen, 2007).	Self-regulation 2 dimensions: - Short term (SR-ST); - Long term (SR-LT).	• In this study the instrument was translated from the original English version into Portuguese language (and back translation). It was then revised by a group of specialized experts within the area and a pre-test in schools with a group of students was conducted. • 36 items answered on a 5-point Likert scale; • Ranges from 36 to 180. • Higher values indicate better competences of self-regulation. • α = .0.79[1]
Scale of Satisfaction with Social Support (SSSS) (Gaspar,Ribeiro, Matos, Leal & Ferreira, 2009; Ribeiro, 1993)	Satisfaction with social support 2 dimensions: - Satisfaction with Social Support (SSS); - Need for Activities connected to Social Support (NASS).	• Translation and adaptation for children and adolescents of a Satisfaction with Social Support Scale for adults; • 12 items answered on a 5-point scale; • Ranges from 18 to 72; • Higher scores indicate higher satisfaction with social support (SSS) or higher satisfaction for not feeling the need to have more social support activities (NASS). • α = .85[1]

[1] Value for the total score of the scale.

Table VIII-8-2. Participant's socio-demographic and clinical characteristics.

Socio-Demographic Variables	**Total Group** (N=135)
Age (years) (M±SD)	14.0±1.5
Gender (%)	
Boy	51.9
Girl	48.1
Educational Level – Adolescents (%)	
Basic 2nd Level (5th-6th Grades)	21.5
Basic 3rd Level (7th-9th Grades)	53.3
Secondary Level (10th-12th Grades)	25.2
Clinical Variables	
Median time of diagnosis (years) (M±SD)	7.5±4.7
Chronic Disease (%)	
Diabetes	31.9
Allergic Diseases	46.7
Neurological Diseases	21.5
Chronic Condition affects SCHOOL (PSCH)? (%)	
No	82.2
Yes	17.8
Chronic Condition affects LEISURE TIME WITH FRIENDS (PLFT)? (%)	
No	86.7
Yes	13.3
KIDSCREEN-52 (Dimensions)	
1) PHY	69.5±16.6
2) PBW	82.5±14.1
3) EMO	82.0±15.5
4) SEL	78.7±15.5
5) AUT	80.6±18.7
6) PAR	85.2±14.5
7) FIN	83.3±19.4
8) SOC	82.6±17.7
9) SCH	74.3±15.2
10) BUL	90.1±17.4
Complementary Psychosocial Scales	
SCL	35.6±4.8
RES	58.4±7.8
SR	119.9±14.4
SSSS	45.1±8.6

AUT – Autonomy; SCL – Symptoms Check-List; BUL – Social Acceptance & Bullying; EMO – Mood & Emotions; FIN – Financial Resources; PAR – Parent relation & Home life; PBW – Psychological well-being; PHY – Physical well-being; SCH – School Environment; SEL – Self-perception; SOC – Social Support & Peers; SR – Self-regulation; SSSS - Satisfaction with Social Support; RES – Resilience.

Table VIII-8-3. Differences between gender on a group of adolescents with chronic disease, for the various dimensions of KIDSCREEN-52 and the complementary psychosocial variables

	Gender[1]		
	Boys	**Girls**	***p***
	N=70	N=65	
KIDS-52 (dimensions)			
1) PHY	**72.6±17.6**	66.2±15.0	0.026*
2) PBW	**85.3±13.1**	79.6±14.6	0.018*
3) EMO	**84.9±14.9**	79.0±15.7	0.026*
4) SEL	**81.7±14.4**	75.5±16.1	0.019*
5) AUT	**87.3±13.3**	73.3±29.9	0.000***
6) PAR	**88.1±13.4**	82.1±15.1	0.015*
7) FIN	**86.7±17.1**	79.6±21.1	0.034*
8) SOC	85.1±15.3	80.0±19.8	0.089
9) SCH	73.6±14.3	75.0±16.2	0.607
10) BUL	91.9±15.6	88.1±19.1	0.206
Complementary Psychosocial Variables			
SCL	**36.6±4.5**	34.5±5.0	0.013*
RES	58.1±7.5	58.7±8.1	0.663
SR	119.6±15.2	120.2±13.6	0.824
SSSS	46.3±8.6	43.7±8.5	0.075

[1] Tested by Independent T-Test.

***p≤.001; **p≤.01; *p≤.05

AUT – Autonomy; SCL – Symptoms Check-List; BUL – Social Acceptance & Bullying; EMO – Mood & Emotions; FIN – Financial Resources; KIDS - KIDSCREEN; PAR – Parent relation & Home life; PBW – Psychological well-being; PHY – Physical well-being; SCH – School Environment; SEL – Self-perception; SOC – Social Support & Peers; SR – Self-regulation; SSSS - Satisfaction with Social Support; RES – Resilience.

Table VIII-8-4. Summary of linear regression analysis for the complementary psychosocial variables predicting the various dimensions of HRQoL (for the total group of adolescents with chronic disease and by gender)

		Total[1]	**Boys[2]**	**Girls[2]**
Kids-52 (Dimensions)		***β***	***β***	***β***
1) PHY	SCL	0.310***	0.264*	0.322**
	RES	0.065	0.1960	-0.160
	SR	0.107	-0.029	0.359**
	SSSS	0.142	0.095	0.198
	R^2	29.9%	26.1%	31.6%
	F	9.158***	5.062***	5.932***
2) PBW	SCL	0.285***	0.434***	0.150
	RES	0.165*	0.212*	0.046
	SR	-0.034	-0.060	0.054
	SSSS	0.449***	0.349**	0.551***
	R^2	52.3%	50.9%	52.7%
	F	22.026***	12.923***	12.900***
3) EMO	SCL	0.394***	0.400***	0.390***
	RES	0.040	0.071	-0.015
	SR	0.033	-0.053	0.149
	SSSS	0.452***	0.445***	0.461***
	R^2	53.6%	54.5%	48.3%
	F	23.113***	14.753***	10.948***
4) SEL	SCL	0.134	0.148	0.126
	RES	-0.041	-0.021	-0.077
	SR	0.019	-0.077	0.133
	SSSS	0.553***	0.604***	0.513***
	R^2	34.3%	42.1%	24.8%
	F	10.991***	7.627***	4.509***
5) AUT	SCL	0.126	0.155	0.113
	RES	0.138	0.255*	0.016
	SR	-0.038	-0.005	-0.025
	SSSS	0.385***	0.278	0.539***
	R^2	46.6%	27.3%	50.6%
	F	17.704***	5.319***	11.935***

6) PAR	SCL	0.163*	0.182	0.147
	RES	0.326***	0.418***	0.245
	SR	0.065	0.051	0.100
	SSSS	0.316***	0.295*	0.343**
	R^2	42.5%	46.4%	32%
	F	15.146***	10.969***	6.012***
7) FIN	SCL	0.032	0.161	-0.073
	RES	0.130	0.107	0.100
	SR	0.131	0.109	0.193
	SSSS	0.255**	0.244	0.258
	R^2	29.2%	25.3%	25.6%
	F	8.901***	4.897***	4.669***
8) SOC	SCL	0.165	0.077	0.201
	RES	0.260**	0.434***	0.049
	SR	-0.131	-0.141	-0.076
	SSSS	0.322***	0.122	0.529***
	R^2	34.2%	22.2%	54.7%
	F	10.967***	4.288***	13.875***
9) SCH	SCL	0.146	0.132	0.161
	RES	0.145	0.105	0.188
	SR	0.308***	0.481***	0.129
	SSSS	0.121	0.015	0.213
	R^2	26.7%	24.4%	28.8%
	F	7.971***	4.716***	5.309***
10) BUL	SCL	0.097	0.222	0.013
	RES	-0.049	-0.259	0.081
	SR	0.108	0.011	0.209
	SSSS	0.111	0.253	0.005
	R^2	10%	14.4%	6.7%
	F	3.130**	2.941*	1.770

β: standardized coefficients.
[1] Analysis were adjusted by gender
[2] Analysis were adjusted by the items "chronic condition affects/not affects participation and attendance at school" (PSCH), and "chronic conditions affects/not affects participation in leisure time with friends" (PLFT).
*** p<0.001; ** p<0.01; * p<0.05

AUT – Autonomy; SCL – Symptoms Check-List; BUL – Social Acceptance & Bullying; EMO – Mood & Emotions; FIN – Financial Resources; KIDS - KIDSCREEN; PAR – Parent relation & Home life; PBW – Psychological well-being; PHY – Physical well-being; SCH – School Environment; SEL – Self-perception; SOC – Social Support & Peers; SR – Self-regulation; SSSS - Satisfaction with Social Support; RES –

Chapter VIII

Research Phase III – Empirical Studies 6-9

Empirical Study 9

Do Clinical And Psychosocial Factors Affect Health-Related Quality Of Life In Adolescents With Chronic Diseases?

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ABSTRACT

Purpose: Living with a chronic disease in adolescence can have an impact on the perception of Health-related Quality of Life (HRQoL). Facing the increasing relevance of psychosocial dimensions and also considering the interaction with clinical variables, this study aimed to measure the impact of clinical and psychosocial factors (separated and combined) on adolescent's reported HRQoL.

Methods: A cross-sectional study was conducted in a clinical population of 135 adolescents with chronic diseases (n=70 boys), average age: 14±1.5 years old. Through a self-reported questionnaire, HRQoL (KIDSCREEN-10), socio-demographic, clinical (diagnostic; time of diagnosis; self-perceived pain; disease severity proxy; disease-related medication intake/use of special equipment), and psychosocial variables (psychosomatic health; resilience; self-regulation; social support) were assessed.

Results: Separately, clinical and psychosocial variables showed a significant impact in HRQoL, 27.9% and 62.4%, respectively. Once combined, the previously identified variables had a significant impact (64.2%), but a different contribution from clinical and psychosocial variables was revealed: when first entering the clinical variables the variance only reaches 30% and much more from psychosocial variables seems to explain the total (64.2%); inversely, when first integrating psychosocial variables, the clinical ones added a small significance to the model (0.6%).

Conclusions: The present study underlined the association of clinical ("disease-related") and psychosocial ("non-disease-related") factors on HRQoL. Furthermore, reinforced the need to focus more on psychosocial dimensions, highlighted the potential role of psychosomatic health, resilience, self-regulation and social support, suggesting that to identify impaired psychosocial domains may help professionals to better plan, and achieve effective interventions of psychosocial care.

Keywords: Adolescents; Chronic Disease; Health-related Quality of Life; Clinical Variables; Psychosocial Variables.

INTRODUCTION

In the last 40 years, advances in pediatric medicine have reduced the mortality rates of many fatal chronic diseases, increasing the survival of youths into adolescence and adulthood [1]. However, living with chronic disease in adolescence still have a significant high risk for poor Quality of Life (QoL) and health-related quality of life (HRQoL) [2-4], especially in psychological functioning [5-7] and social dimensions [8,9]. HRQoL is generally conceptualized as a multidimensional psychological construct including physical, mental, social and spiritual areas of life and general well-being [10-12]. Additionally, the adolescent-friendly health service concept [13] suggests the need to include physical, psychological, and social perspectives. Relying on the World Health Organization's (WHO) definitions of health [14], QoL and HRQoL are important constructs given their implications for health outcomes, well-being and a successful daily life in adolescents [15,16].

The aspects comprising HRQoL in chronically ill adolescents can be divided into two factors: disease-related factors, such as age of onset, disease severity, complications, treatment, sense of normality and positive attitude towards the disease, and non-disease-related factors (age, gender, socioeconomic status, support of parents, social wellbeing and support [17]. Recent literature has enlightened disease-specific determinants of HRQoL, such as physical ability, pain, subjective burden of medication use [18], diagnosis [19-21], severity of the disease [4,21,22], school absence [18,23] and illness perception [7]. In addition, non-disease factors were also considered as determinants for HRQoL, namely anxiety/depression [24], gender [7,21], age [2,5,21], socioeconomic status [19,21], quality of peer relationship [25], social interaction/social support [3,8,22] and parents' support [7,26].

Nevertheless, in youth, perceptions of HRQoL can be influenced by a dynamic interdependence between several demographic, personal and social factors [11,12,27,28], and as a child advances in age, psychosocial elements seem to be more important for self-perceived QoL than biomedical/physical factors [29]. Thus, psychosocial variables can assume a crucial role, more than the presence, *per se*, of the physical dimensions of the health condition [30-32]. As a result, chronic disease's assessment should be less focused on diagnostic categories (where more variability exists), and more on the impact that the disease might have on the socialization process, emotional health, and general limitations in ordinary activities [30,33]. Supporting this idea, clinical settings have been progressively recognizing the need to complement traditional health indicators with psychosocial factors [34,35], which requires a routinely assessment in

pediatric contexts [4,5]. Moreover, to include such factors in clinical decision making and research is necessary, mainly because managing symptoms and improving psychosocial care are now primary goals of interventions [3,34-37].

Facing the increasing relevance of psychosocial dimensions, but also taking into account the interaction with clinical variables, this study aimed to measure the impact of clinical and psychosocial factors (separated and combined) on adolescent's reported HRQoL.

METHODS

Participants, Design and Procedure

This cross-sectional study included 135 chronically ill adolescents (*n*=70 boys) with a mean age of 14 (SD=1.5) years old, attending a clinical appointment in the paediatric outpatient department of *Centro Hospitalar Lisboa Norte* – CHLN EPE (North Lisbon Central Hospital), with diagnosed neurologic diseases, allergic diseases or diabetes *mellitus*. The focus on these chronic diseases was based on the evidence of their high prevalence in adolescence [38]. The majority of the adolescents had Portuguese nationality (*n*=132), lived in Lisbon (*n*=114) and attended the 7^{th}-9^{th} school grades (*n*=72).

Prior to data collection, ethical approval for this study was obtained from The Ethics Committee for Health from CHLN-EPE, the institution's ethical committees (Compliance with Ethical Standards: Reference PCA-12 Nov.2012-0785). Accordingly with the World Medical Association Declaration of Helsinki's guidelines [39], the description of the study's aims and participants' rights was delivered. The participation was voluntary and the agreement and informed consent required by the ethical committee was filled by both adolescents and their parents. Participants were then selected and approached directly by their health professionals (physicians and/or nurses) during the medical appointments. Health professionals (paediatricians) help to identify the following applied inclusion criteria: 1) diagnosis of chronic disease (diabetes, allergic diseases and neurologic diseases); 2) age between 12 and 16 years old at the time of the study, including both age groups of young teens (12-14 years old) and teenagers (15-17 years old), defined by the Centers for Disease Control and Prevention – CDC [40]; 3) have cognitive skills to fill the questionnaire autonomously. Data was collected using a self-reported questionnaire, either after or before the medical appointment according to the

most convenient moment, and research assistance was available to provide support whenever necessary.

Measures

The self-reported questionnaire was completed by adolescents, including the assessment of HRQoL, socio-demographic, clinical and psychosocial variables. Socio-demographic variables comprised age, gender, geographic region, nationality, education level of adolescents, and educational level of adolescent's parents (a proxy for socioeconomic status).

Clinical variables consisted of diagnosis, time since diagnosis, self-perceived pain, disease-related use of special equipment, and the following 3 items: 1) disease-related medication intake; 2) "Does your long-term illness, disability or medical condition affect your attendance and participation in leisure activities with friends, classmates (PLTF)? No/Yes"; 3) "Does your long-term illness, disability or medical condition affect your attendance and participation at school (PSCH)? No/Yes". These three items are included in the international study Health Behaviour in School-aged Children - HBSC/WHO [41,42], and items 1 and 3 constitute its optional package The Chronic Condition Short Questionnaire (CCSQ) [43]. These items focused on the disease's consequences (missing school classes, medication), allow assessing the impact of a chronic health condition on the adolescents' activities and help to understand its psychosocial impact, showing considerable strengths over a single, open-ended item. Furthermore, co-existing problems related to medication intake, and/or missing school classes are reported as good indicators of severity [42], thus, all of these items together were considered in the present study as a proxy for disease's severity. To assess Self-perceived Pain, it was used a combination of the most common Pain's Perception Analogic Scales suggested in the literature [44-46], namely the Visual Analogue Scale (VAS), the Numerical Rating Scale (NRS) [47,48], and the Faces Scale of Wong-Baker [49], which are also in accordance with the recommendation of the Portuguese Health Ministry [50]. Due to the small size of the sample, the adolescents were grouped not by categories of disease's intensity, but according to feeling or not feeling pain.

The psychosocial variables (described in detail in **Table 1**) included Health-related Quality of Life-HRQoL (KIDSCREEN-10 Index), Symptoms Check-List (Psychosomatic Health Complaints - SCL), Resilience (Scale Healthy Kids Resilience Assessment Module -

RES), Self-regulation (Scale Adolescent Self-Regulatory Inventory-ASRI, SR), and Social Support (Scale of Satisfaction with Social Support-SSSS).

[Table 1 near here]

Statistical Analysis

Descriptive statistics (means, standard deviation and percentage) were used to characterize the sample. All data were tested for normality prior to any analyses using Shapiro-Wilk and Kolmogorov-Smirnov tests, as well as Levene's test for the homogeneity of the variance. In a first moment, multiple linear regressions were used to assess, separately, the extent to which clinical and psychosocial variables were associated with health-related quality of life (HRQoL) for the total group of adolescents. Later, two more multiple linear regressions were conducted only using the previously identified significant clinical and psychosocial variables. The first model comprised two steps: in the first step were included the clinical variables and in the second step added the psychosocial variables; in the second model both steps were entered inversely. Multiple linear regressions were controlled for age and gender. The categorical variables were transformed into dummy variables. All statistical analyses were completed using IBM Statistical Package for Social Sciences (SPSS), version 22.0. The significance level was set at $p<0.05$.

RESULTS

The socio-demographic and the clinical variables included in the study for the total group of adolescents are presented in **Table 2**.

[Table 2 near here]

This study included 135 adolescents having three diagnosed chronic diseases: diabetes (*n*=43), allergic diseases (*n*=63), or neurologic diseases (*n*=29), had a mean time of diagnosis of 7.5 (SD=4.7) years, the majority takes medication (*n*=88) and generally did not use special equipment (*n*=83) related to the chronic disease. Most of them felt that living with a chronic disease did not affect school participation - PSCH (*n*=111), nor social participation - PLTF (*n*=117).

Table 3 shows the results of the linear regression analysis, in separate, for clinical and psychosocial variables, for the total group of adolescents with chronic diseases, adjusted by age and gender.

[Table 3 near here]

A model was achieved for clinical variables [$F(10,123)=6.157$, $p<0.001$, $R^2=.279$]. The variables self-perceived pain and the items PSCH and PLTF had a significantly association: the adolescents that did not have Self-Perceived Pain, nor felt that the disease affected PSCH, tended to have a higher perception of their HRQoL. No differences were found for the variables time since diagnosis, disease-related use of special equipment or medication intake.

A model was also achieved for the psychosocial variables [$F(8,117)=26.917$, $p<0.001$, $R^2=.624$]. The variables SCL, RES, SR and SSSS had a significantly association: adolescents with better psychosomatic health (reporting less symptoms), higher levels of resilience, self-regulation and social support were more likely to perceive their HRQoL as more satisfying. No differences were found for the educational level (father or mother).

Tables 4 and **5** show the summary of results between HRQoL and the previously identified significant clinical (step 1) and psychosocial variables (step 2).

[Table 4 near here]

[Table 5 near here]

In the step 1 of **Table 4** an adequate model was achieved [$F(5,129)=12.472$, $p=0.000$, $R^2=.300$]. Self-perceived pain and the items PSCH and PLTF had a significant association: the adolescents that did not have Self-Perceived Pain, nor felt that the disease affected PSCH, tended to have a higher perception of their HRQoL. An adequate model was also achieved in the step 1 of **Table 5** [$F(4,130)=59.509$, $p=0.000$, $R^2=.636$]. The psychosocial variables SCL, RES and SSSS had a significant association: the adolescents reporting higher scores for psychosomatic health, resilience and social support had a tendency to perceive a higher HRQoL, and no differences were found for SR.

In both step 2 of **Tables 4** and **5** an adequate model was [$F(9,125)=27.744$, $p<0.001$, $R^2=.642$]. The psychosocial variables SCL, RES and SSSS had a significant association: the adolescents reporting higher scores for psychosomatic health, resilience and social support had

a tendency to perceive a higher HRQoL. No differences were found for Self-Perceived Pain, PSCH/PLTF and SR.

DISCUSSION

The present study aimed to measure the impact of clinical and psychosocial factors (separated and combined) on adolescent's reported HRQoL.

A brief overlook of the results shows that, separately, both clinical and psychosocial variables have a significant association with the perception of HRQoL, showing high values of explained variance (respectively 27.9% and 62.4%). Self-perceived pain and the items PSCH/PLTF (proxy for disease's severity) were the significant clinical variables impacting HRQoL, whereas SCL, RES, SR and SSSS were the most significant psychosocial ones. These findings are in accordance with literature, which indicated that perceptions of HRQoL can be influenced by several factors [11,12,27,28]. Also reinforce the suggestions in the literature to assess both disease related and non-disease-related factors [17], including physical, psychological and social perspectives [13], as well as limitations in ordinary activities [30,33]. In addition, it highlights that adolescents living with a chronic condition may have a high risk for poor perceptions of HRQoL, also pointed out in previous research [2-4,29,63].

Interestingly, when combining the above identified significant clinical and psychosocial variables in a multilinear regression models (step 2 of Model 1 and 2), a significant association with a high value of explained variance was obtained (64.2%). Clinical variables were no longer significant and the psychosocial variables SCL, RES and SSSS (with exception of SR) maintain their association with HRQoL's perception. To achieve such result, a different contribution from both clinical and psychosocial variables was revealed (step 1 of both Model 1 and 2). When first entering the clinical variables the variance only reaches 30% and much more from psychosocial variables seems to explain the total of 64.2%; inversely, when first entering the psychosocial variables, the clinical ones add a small significance to the model (only 0.6%)

Such findings suggest a dynamic interdependence between these different elements, as stressed out in the literature [11,12,27,28], although pointing out a higher relevance of non-disease-related factors, thus, supporting the suggestions in the literature emphasizing more the importance to focus on the disease's impact on psychosocial dimensions, and less on the diagnostic categories/physical dimensions [30,31,33]. In addition, they underline previous

research recommendations, namely the need to include psychosocial factors in complement of health indicators [34,35], and the relevance of routinely conduct its assessment in clinical and pediatric settings [4,5,7].

The observed significance of psychosocial variables in the present study can also be understood taking into account The Asset Model [64], which draws attention to the role of protective factors that can predict positive health outcomes and improve coping skills, in chronically ill adolescents [65]. Additionally, the results of the present research are in line with previous studies reporting the importance of such protective factors, namely psychosomatic health [66], resilience [67-69], self-regulation [70,71] and social support [26,72]. Resilience, social support, symptom's control and self-management may allow a good adaptation while facing adverse health conditions and potentially stressful new situations, and help to reduce stress, increase control and improve outcomes in HRQoL. Therefore, these variables can be considered promising candidates for future interventions [15,67,68,73]. In addition, it may be suggested somehow a relationship between SR, the educational level of parents and the clinical variables (that need to be studied with more detail), considering that this psychosocial variable was no longer significant in the step 1 of Model 1 and in step 2 of both models. Literature previously indicated that adolescents with chronic conditions who need to develop more disease-related skills (e.g. insulin assessment/intake) and adhere to multiple complex daily tasks, require high levels of self-management and regulation competencies [73].

Facing these results, the present study accentuates a higher relevance of non-disease-related factors, supporting the suggestions in the literature to emphasize more the disease's impact on psychosocial dimensions and less the diagnostic categories/physical dimensions [30,31,33]. In addition, it also underlines previous research recommendations, proposing that in the specific period of adolescence [74,75], it is crucial to include psychosocial dimensions in complement of traditional health indicators [34,35,37,63], and to routinely conduct its assessment in clinical and pediatric settings [4,5]. Furthermore, to identify the impaired psychosocial domains, can give potentially useful suggestions, that better help to plan and guide interventions aiming to improve an integral perspective that represents the holistic care for these adolescents [2,3,36,43].

Limitations and Strengths

This study had some limitations. This was a clinical convenience sample therefore probable generalizations should take that into account. Recall bias might be introduced through self-report, and some adolescents were under-represented, due to the group's heterogeneity (different diseases/limitations). The cross-sectional design of the study precludes inferences concerning causality and longitudinal data would be needed. This study has however numerous strengths, namely including self-reports from adolescents and well-developmentally appropriate measures [76] for HRQoL, psychosomatic health, resilience, and social support, focusing on potentially protective factors for health outcomes, suggested in the literature.

In forthcoming research it would be important to replicate these variables in a larger sample and in specific populations, in order to conduct more valid analyses for the included clinical/psychosocial variables and for additional ones, aiming to increase understanding of the potential differences in these groups. Also due to the cross-sectional design of the present study, more research is needed to highlight the interaction and reciprocal potentially effects of chronic disease and adolescent developmental changes, because the disease can affect this age process and the reserve is also true [16].

Conclusions

The present research supports suggestions in the literature that underlined the relevance of assessing psychosocial domains as a complement to traditional health indicators. In addition, it draws attention to potential protective factors for health outcomes. To identify impaired psychosocial domains in adolescence, and conduct further research on these variables may reveal crucial strategies used by successfully adapted adolescents that can help planning psychosocial care for those who struggle. Furthermore, to better help professionals addressing adolescent's needs and to plan and adjust interventions, increasing their effectiveness.

Abbreviations

CHLN EPE: Centro Hospitalar Lisboa Norte

HRQoL: Health-related Quality of Life

KIDS-10: KIDSCREEN Index

QoL: Quality of Life

RES: Healthy Kids Resilience Assessment Module

SCL: Symptoms Check List-HBSC-SCL (Psychosomatic Complaints)

SR: Adolescent Self-Regulatory Inventory (ASRI)

SSSS: Scale of Satisfaction with Social Support

WHO: World Health Organization

WMA – World Medical Association

Author's contributions

TS and MGM conceived the study, participated in its design and coordination, draft and authored the manuscript; AM helped to perform statistical analyses, participated in interpretation of data and helped to draft manuscript revisions; CS participated in the study design, interpretation of the data, and helped to draft manuscript revisions; IL and MCM participated in the study design and helped to draft manuscript revisions. All authors have read and approved the final manuscript.

Competing interests

None of the authors reported any financial interests or potential conflicts of interest.

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Ethical approval

All procedures in the present study were performed in accordance with the ethical standards of the institutional and/or national research appropriate committee (The Ethics Committee for Health from CHLN-EPE, Reference PCA-12 Nov.2012-0785), and with the 1964 Helsinki declaration and its later

amendments or comparable ethical standards. Written informed consent was obtained from all individual participants included in the study (both adolescents and their parents/legal guardians). For this type of study, formal consent from adolescents under 14 years old was not required.

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Table VIII-9-1. Psychosocial Variables

Name	Psychosocial Measure	Abbreviation (in this study)	Short Description
KIDSCREEN-10 Index [51,52,53]	Health-related quality of life – HRQoL	KIDS-10	• Short version of KIDSCREEN-52; • Used in the HBSC/WHO Study [54,55]; • 10 items, on a 5-point Likert-type scale; • Ranges from 0 to 100; • Lower values reflect feelings of unhappiness, dissatisfaction and inadequacy. Higher values show feelings of happiness, perception of adequacy and satisfaction within adolescent's life contexts. • $\alpha = .83$
Symptoms Check List (SCL-HBSC) [56,57]	Psychosomatic complaints (unidimensional latent trait).	SCL	• Used in the HBSC/WHO [54,55]; • 8 items focusing on subjective physical and psychological health complaints; • Each item answered on a 5-point Likert-type response scale; • Resulting values between 1 (worst health) and 5 (best health); • Ranges from 8 to 40. • $\alpha = .78$
Healthy Kids Resilience Assessment Module [58,59]	Resilience (2 dimensions: external and internal resources).	RES	• The present study only used the internal resources; • 18 items answered on a 4-point scale; • Ranges from 18 to 72; • Higher scores indicate higher levels of competences, protection and resilience to adversity. • $\alpha = .0.72$[1]
Adolescent Self-Regulatory Inventory – ASRI [60]	Self-regulation (2 dimensions: Short term-SR-ST and Long term-SR-LT).	SR	• In this study the instrument was translated from the original English version into Portuguese language (and back translation). It was then revised by a group of specialized experts within the area and a pre-test in schools with a group of students was conducted. • 36 items answered on a 5-point Likert scale; • Ranges from 36 to 180. • Higher values indicate better competences of self-regulation. • $\alpha = .0.79$[1]
Scale of Satisfaction with Social Support [61,62]	Satisfaction with social support (2 dimensions: Satisfaction with Social Support-SSS; and Need for Activities connected to Social Support-NASS).	SSSS	• Translation and adaptation for children and adolescents of a Satisfaction with Social Support Scale for adults; • 12 items answered on a 5-point scale; • Ranges from 18 to 72; • Higher scores indicate higher satisfaction with social support (SSS) or higher satisfaction for not feeling the need to have more social support activities (NASS). • $\alpha = .85$[1]

[1] Value for the total score of the scale.

Table VIII-9-2. Participant's socio-demographic and clinical characteristics

	Total Group
Socio-Demographic Variables	
Age (years) (M±SD)	14.0±1.5
Gender (%)	
Boy	51.9
Girl	48.1
Geographic Region (%)	
Lisbon	84.4
Rest of the Country	15.6
Nationality (%)	
Portuguese	97.8
Others	2.2
Educational Level – Adolescents (%)	
Basic 2nd Level (5th-6th Grades)	21.5
Basic 3rd Level (7th-9th Grades)	53.3
Secondary Level (10th-12th Grades)	25.2
Educational Level – Father[1] (%)	
Basic Level (1st-9th Grades)	64.6
Secondary Level (10th-12th Grades)	23.6
Superior (or more) Level (Universitary, Post-Graduate)	11.8
Educational Level – Mother[1] (%)	
Basic Level (1st-9th Grades)	53.8
Secondary Level (10th-12th Grades)	29.5
Superior (or more) Level (Universitary, Post-Graduate)	16.7
Clinical Variables	
Chronic Condition diagnosis (%)	
Diabetes	31.9
Alergic Diseases	46.7
Neurologic Diseases	21.5
Time since diagnosis (years) (M±SD)	7.5±4.7
Self-perceived pain (%)	
No	43.0
Yes	57.0
Disease-related use of special equipment (%)	
No	61.5
Yes	38.5
Disease-related medication intake[1] (%)	
No	34.8
Yes	65.2
Chronic Condition affects SCHOOL (PSCH)[2]? (%)	
No	82.2
Yes	17.8
Chronic Condition affects LEISURE TIME WITH FRIENDS (PLTF)[2]? (%)	
No	86.7
Yes	13.3
Psychosocial Variables (M±SD)	
SCL	35.6±4.8
RES	58.4±7.8
SR	119.9±14.4
SSSS	45.1±8.6
HRQoL (M±SD)	
KIDSCREEN – 10	79.7±12.5

HRQoL – Health-related Quality of Life; KIDS-10 - KIDSCREEN; PSCH - "chronic condition affects/not affects participation and attendance at school"; PLTF - "chronic conditions affects/not affects participation in leisure time with friends"; RES - Resilience; SCL - Symptoms Check List; SR - Self-regulation; SSSS – Scale of Satisfaction with Social Support.

[1] Considered as a proxy of socioeconomic status.
[2] Considered as a proxy of disease's severity.

Table VIII-9-3. Summary of multiple linear regression results between HRQoL and clinical and psychosocial variables (separately), in adolescents with chronic disease, adjusted by age and gender.

	Clinical Included Variables	***B***	***SE B***	***β***
HRQoL	Diagnostic (asthma disease)	2.519	4.372	0,101
	Diagnostic (neurologic disease)	4.346	4.036	0.144
	Diagnostic (diabetes)	-2.519	4.372	0.566
	Time since diagnostic (years)	-0.100	0.219	-0.038
	Disease-related medication intake[1]	0.741	2.707	0.028
	Disease-related use of special equipment[2]	2.518	3.537	0.098
	Self-perceived Pain[3]	-5.192	1.940	-0.206**
	PSCH[4]	-9.456	2.835	- 0.291***
	PLTF[5]	-7.968	3.352	- 0.218*
	R^2			27.9%
	F			6.157***
	Psychosocial Included Variables	***B***	***SE B***	***B***
HRQoL	SCL	0.761	0.161	0.295***
	RES	0.285	0.105	0.183**
	SR	0.126	0.056	0.149*
	SSSS	0.595	0.100	0.412***
	Educational Level – Father	-0.391	0.866	-0.032
	Educational Level – Mother	-0.523	0.864	-0.042
	R^2			62.4%
	F			26.917***

Note. *B* (unstandardized coefficient) and *SE* (standard error); *β*: standardized coefficients.

***p≤.001; **p≤.01; *p≤.05

Analysis were adjusted for age and gender.

[1] No Use of medication was used as the reference group.

[2] No Use of special equipment was used as the reference group.

[3] No self-perceived pain was used as the reference group.

[4] Not affecting SCH was used as the reference group.

[5] Not affecting LTF was used as the reference group.

Table VIII-9-4. Summary of multiple linear regression results between HRQoL and the previously identified significant clinical (step 1) and psychosocial variables (step 2), in adolescents with chronic disease, adjusted by age and gender (Model 1)

	Model 1							
	(Step 1 - Clinical Variables)				**(Step 2 - Clinical and Psychosocial Variables)**			
	Variables	***B***	***SE B***	***β***	**Variables**	***B***	***SE B***	***β***
HQoL	Self-perceived Pain[1]	-5.182	1.883	-.206**	Self-perceived Pain[1]	0.483	1.510	0.019
	PSCH[1]	-9.380	2.747	-.288***	PSCH[1]	-2.322	2.208	-0.071
	PLTF[1]	-7.172	3.082	-.196*	PLTF[1]	-0.384	2.323	-0.011
					SCL[2]	0.723	0.179	0.280***
					RES[2]	0.300	0.102	0.188**
					SR[2]	0.101	0.056	0.116
					SSSS[2]	0.589	0.100	0.408***
	R^2			.300	R^2			.642
	F			12.472***	***F***			27.744***

Note. *B* (unstandardized coefficient) and *SE* (standard error); *β*: standardized coefficients.
***p≤.001; **p≤.01; *p≤.05
Analysis were adjusted for age and gender.

[1] Clinical Variables
[2] Psychosocial Variables

HRQoL – Health-related quality of life; PLTF - "chronic conditions affects/not affects participation in leisure time with friends"; PSCH - "chronic condition affects/not affects participation and attendance at school"; SCL – Symptoms Check-List; SSSS - Satisfaction with Social Support; SR – Self-regulation; RES – Resilience.

Table VIII-9-5. Summary of multiple linear regression results between HRQoL and the previously identified significant psychosocial (step 1) and clinical variables (step 2), in adolescents with chronic disease, adjusted by age and gender (Model 2)

	Model 2							
	(Step 1 - Psychosocial Variables)				**(Step 2 – Psychosocial and Clinical Variables)**			
	Variables	***B***	***SE B***	***β***	**Variables**	***B***	***SE B***	***β***
HQoL	SCL[2]	.859	.148	.333***	SCL[2]	.723	.179	.280***
	RES[2]	.274	.101	.171**	RES[2]	.300	.102	.188**
	SR[2]	.100	.053	.116	SR[2]	.101	.056	.116
	SSSS[2]	.636	.094	.440***	SSSS[2]	.589	.100	0.408***
					Self-perceived Pain[1]	0.483	1.510	0.019
					PSCH[1]	-2.322	2.208	-0.071
					PLTF[1]	-0.384	2.323	-0.011
	R^2			.636	R^2			.642
	F			59.509***	***F***			27.744***

Note. *B* (unstandardized coefficient) and *SE* (standard error); *β*: standardized coefficients.
***p≤.001; **p≤.01; *p≤.05
Analysis were adjusted for age and gender.

[1] Clinical Variables
[2] Psychosocial Variables

HRQoL – Health-related quality of life; PLTF - "chronic conditions affects/not affects participation in leisure time with friends"; PSCH - "chronic condition affects/not affects participation and attendance at school"; SCL – Symptoms Check-List; SSSS - Satisfaction with Social Support; SR – Self-regulation; RES – Resilience.

PART III – DISCUSSION AND CONCLUSIONS

Chapter IX

Summary and Integrated Discussion of the Main Findings

In Part III of the present dissertation, an overview and integrative discussion of the main findings will be presented. The findings provided by the nine scientific articles addressed the impact of living with chronic disease on HRQoL, subjective health constructs and psychosocial development, particularly during the context of a developmental crucial age period – Adolescence (Carona et al., 2013; Michaud et al., 2007; Suris et al., 2004). Such findings will be presented in conformity with the aforesaid specific aims, without overlapping with the previously detailed discussion presented in the Part II, and aiming to progress the discussion of results. Subsequently, limitations and strengths of the present dissertation will be critically commented, as well as future research possibilities and the implications for clinical practice and public policy.

1. Summary of the Main Findings

The **first aim** of the present research was to explore and characterize the psychosocial functioning of adolescents with chronic disease, through the analyses of the HBSC/WHO-Portuguese Survey 2010, aiming to contribute to the knowledge of Portuguese reality at a national representative level. For that purpose four articles were conducted (empirical studies 1, 2, 3 and 4) and the most relevant findings are summarized below.

Individual-Psychological Level (empirical studies 1, 2)

- ***Comparisons between adolescents having/not having chronic disease (cases vs. controls):*** *Life Satisfaction (studies 1, 2).* No differences were found between the two groups. Mostly older adolescents, girls and those who had a lower socioeconomic status (FAS/SES) tended to perceive their lives as less satisfying (no association was found for having/not having a chronic disease).

Wellness Perception (studies 1, 2). Adolescents with chronic condition reported lower wellness perception. Mostly girls, older adolescents, those with a chronic disease and having a lower socioeconomic status (FAS/SES), tended to feel more frequently unwell.

HBSC Symptom Check-list (SCL) (selected items) (study 2). Adolescents with chronic disease reported higher frequency of symptoms (namely feeling sad, irritated, nervous and fearful).

- ***Comparisons between adolescents feeling that disease affects/not affects participation and regular attendance of school (only cases):***

  Life Satisfaction (studies 1, 2). Adolescents who felt that disease did not affect their participation and regular attendance to school reported a higher life satisfaction. Mostly older adolescents, those who had a lower socioeconomic status (FAS/SES) and those who felt that disease affected school, did show a worse perception of life satisfaction.

  Wellness Perception (studies 1, 2). Adolescents who felt that disease affected their participation and regular attendance of school, reported a lower wellness perception. Mostly older adolescents, girls, and the ones who reported that disease affected school, tended to feel more frequently unwell.

  HBSC Symptom Check-list (SCL) (selected items) (study 2). Adolescents who felt that disease affected school participation reported a higher frequency of symptoms (namely feeling sad, irritated, nervous and fearful).

Socio-Contextual Level (empirical studies 3, 4)

- ***Comparisons between adolescents having/not having chronic disease (cases vs. controls):***

  Satisfaction with the Family Environment (study 3). Adolescents with chronic disease reported lower perception of satisfaction with family environment. Mostly in older adolescents, girls, and in those with a lower socioeconomic status (FAS/SES) and chronic disease, it was reported a worst satisfaction with family environment.

  Pressure with Schoolwork (study 3). Adolescents with chronic disease reported feeling more pressure with school homework. Mostly older adolescents, girls, the ones without chronic disease and having a higher socioeconomic status (FAS/SES), reported higher pressure with schoolwork.

Perceived School Performance (study 3). No differences were found between the two groups. Mostly older adolescents and the ones who had a lower socioeconomic status (FAS/SES) tended to present a poorer perception of school performance.

Cluster of Risk Behaviours ("drunkness, physical fight, self-harm and sadness") (study 4). Adolescents with chronic disease had more internalizing than healthy behaviours, when compared with their healthy peers. Boys with chronic disease had more frequently healthy-behaviours, although the ones with no chronic disease tended to report more risky-behaviours. Girls with chronic disease reported more internalizing than healthy behaviours, comparing with the others with no chronic disease.

- ***Comparisons between adolescents feeling that disease affects/not affects participation and regular attendance of school (only cases):***

  Satisfaction with the Family Environment (study 3). Adolescents who reported that disease affected school participation felt lower perception of satisfaction with family environment. Mostly older adolescents, those with a lower FAS/SES and feeling that the disease affected school tended to perceive a worse perception of satisfaction with family environment.

  Pressure with Schoolwork (study 3). No differences were found between the two groups and older adolescents and girls more frequently tended to feel a higher pressure with schoolwork.

  Perceived School Performance (study 3). Adolescents who perceived that disease affected school participation felt more frequently a student below average. Mostly younger adolescents and the ones with higher FAS/SES reported worse perception of school performance.

  Cluster of Risk Behaviours ("drunkness, physical fight, self-harm and sadness") (study 4). Adolescents with chronic disease and feeling that it affects school participation tended to more frequently show risky, than healthy behaviours. Boys whose attendance and participation in school were affected, had more frequently risky behaviours, whilst the ones whose participation was not affected, presented more healthy behaviours.

The **second aim** of the present work was to clarify the possible associations between living with chronic disease and its impact on QoL/HRQoL and psychosocial factors, especially in the specific age group of adolescents. For that purpose, a systematic review of the literature was conducted of original quantitative peer-reviewed research papers, written in English,

Portuguese or Spanish, published between 2010 and 2015, and reporting on associations between chronic disease in adolescence and QoL/HRQoL and psychosocial factors. The most important findings will be consequently presented.

- Most of the included studies pointed out a significantly higher risk of impairment in HRQoL/QoL, in psychological and also in social functioning. Nevertheless, other studies pointed no significant differences and even significantly lower risk of impairment. In what concerns this last category, the satisfactory (or even moderate to high) outcomes can be explained taking into account potentially protective factors.
- These ambiguous results can also be partially explained taking into account the high levels of heterogeneity across studies, despite the efforts to organize information, conducted in research in the last years.
- Wide age ranges were employed (presenting separate results for each age group), and only some studies focused on the specific adolescent's developmental stage, foreseeing difficulties in isolating this specific age, and observing a considerable inconsistent approach to age group specificities.
- Regardless of controversial findings, both disease-related and non-disease related factors were underlined as predictors for HRQoL.

The **third aim** of the present research was to explore and characterize HRQoL and psychosocial factors, including protective ones reported in the literature, specifically in a population of adolescents with chronic diseases in an outpatient department in hospital context. For that purpose four articles were carried out (empirical studies 6, 7, 8 and 9), and the most relevant findings are summarized below.

HRQoL, SCL, RES, SR and SSSS (empirical studies 6-9)

- ***Comparisons between the three groups of chronic diseases (categorical approach):***
  General findings (study 6). Adolescents with diabetes reported higher levels of self-regulation (both general self-regulation and short-term self-regulatory strategies), when compared with those with allergic diseases (but not with the ones with neurological diseases). No further differences were found in HRQoL and in other psychosocial variables for the three groups of chronic diseases.

- ***Combining the three groups of chronic diseases (non-categorical approach):***

  General findings (study 6). Boys tended to report a higher HRQoL and better psychosomatic health than girls. Adolescents who used special equipment presented higher self-regulation competencies, compared with those that did not use it. No statistically differences were found for the variables age, educational level of the adolescents, educational level of the mother and educational level of the father, time since diagnosis and medication used to treat the disease.

  Comparisons between disease affecting/not affecting school and social participation (study 7). Adolescents who felt that disease did not affected either school or social participation, tended to report higher HRQoL, better psychosomatic health, higher resilience, higher self-regulation competences and greater social support. In what concerns school participation, self-regulation and psychosomatic health were the most important variables explaining such association, whereas social support was the sole and central variable, regarding social participation.

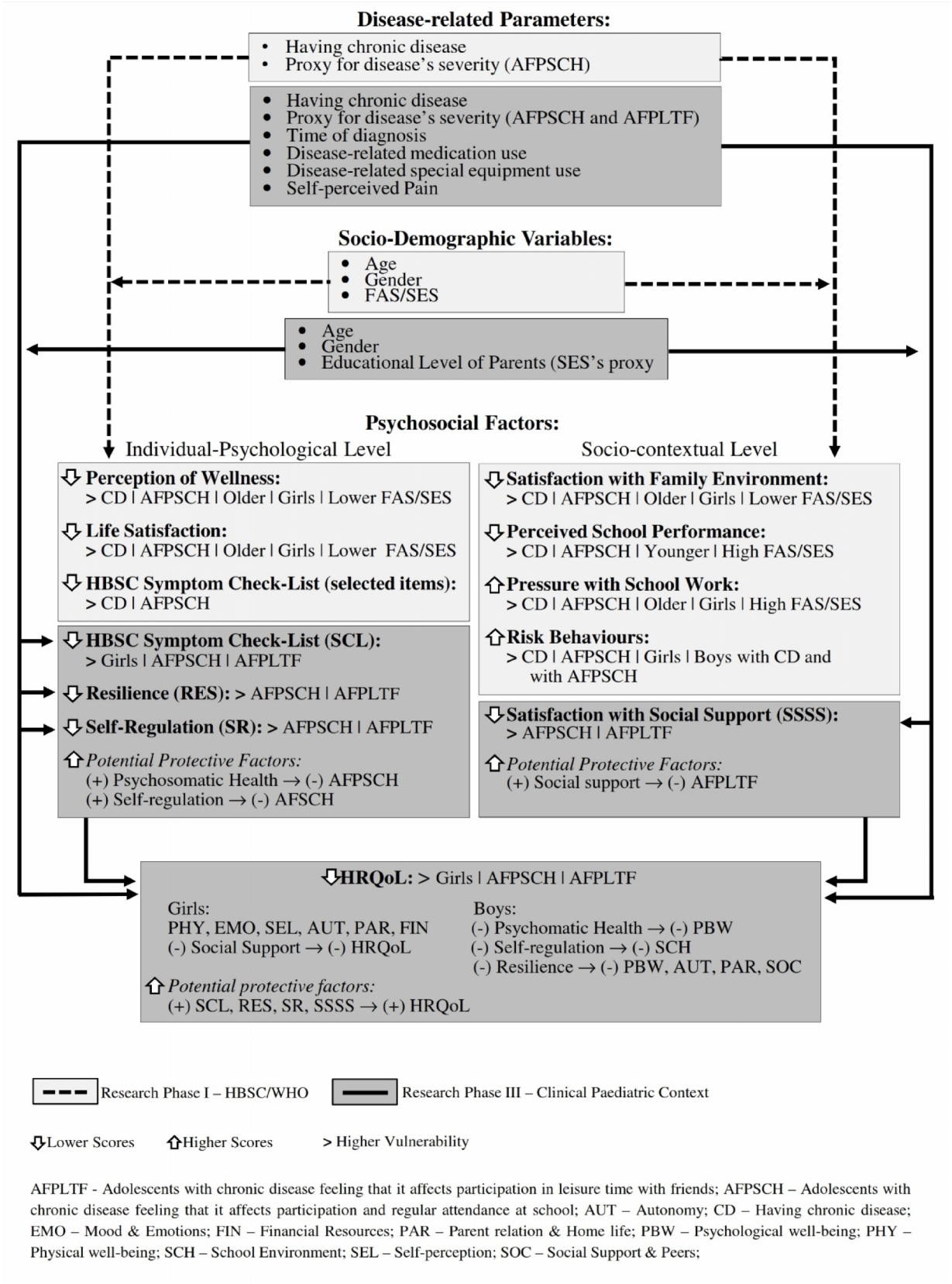
  Gender differences (studies 6, 8). Girls tended to report worse HRQoL and psychosomatic health, when compared to boys (study 6). Interestingly, when controlling for affecting/not affecting school and social participation, although girls in general still reported a poor perception on most of HRQoL's dimensions, the interesting feature was that significant differences were revealed only for the boys' subgroup. (study 8).

  Relevance of psychosocial variables (study 9). In separate, both clinical and psychosocial variables showed a significant impact on HRQoL's perceptions. Once combined, the identified significant variables had an important impact, but mostly explained by psychosocial variables and afterwards, clinical ones added a small variance to the model.

Finally, **Figure IX-1** depicts the conceptual integration of the main research findings of the empirical studies in Research Phases I and III, grouped in topics in compliance with the outlined specific aims and to improve the discussion of the results. This figure also presents the principal indicators of vulnerability in adolescents with chronic diseases.

The discussion of the possible effects of living with a chronic disease on HRQoL and psychosocial factors will be discussed in more detail in the following sections.

Figure IX-1. Conceptual integration of the main findings presenting possible indicators of vulnerability in adolescents with chronic diseases (Research Phases I and III, empirical studies 1-4; 6-9).



AFPLTF - Adolescents with chronic disease feeling that it affects participation in leisure time with friends; AFPSCH – Adolescents with chronic disease feeling that it affects participation and regular attendance at school; AUT – Autonomy; CD – Having chronic disease; EMO – Mood & Emotions; FIN – Financial Resources; PAR – Parent relation & Home life; PBW – Psychological well-being; PHY – Physical well-being; SCH – School Environment; SEL – Self-perception; SOC – Social Support & Peers;

2. Integrated Discussion of the Main Findings

2.1. Characterization of Psychosocial Functioning in Portuguese Adolescents (National-Representative Level)*

* The present set of studies were greatly benefited from the connection with the *Aventura Social* research team (the Portuguese HBSC Team), and during the period of this work, with the scientific discussions and shared knowledge with other researchers within the international HBSC network, mainly the *Chronic Condition Writing Group* (under the Coordination of Professor Dr. Emmanuelle Godeau).

The discussion of the empirical studies 1, 2, 3 and 4 will be grouped according to an individual-psychological level and a socio-contextual level.

Regarding the **individual-psychological** level and in front of the obtained results in the set of studies 1 and 2, it was observed that having a chronic disease was associated with poor wellness perception, life satisfaction and psychological well-being. This evidence found support in literature, which indicated that living with a chronic disease can increase vulnerability for emotional and psychological healthy development (Barlow & Ellard, 2006; Bersnstein et al., 2011; Oeseburg et al., 2010; Verhoof et al., 2012), leading to worse life satisfaction and more internalized symptoms (Verhoof et al., 2013), such as depression (Myiazaki et al., 2006; Vanhalst et al., 2012), and anxiety (Lavigne & Faier-Routman, 1992). Literature also showed that such risk factor might continue later in adulthood (Verhoof et al., 2013). Additionally, the present findings were also consistent with previous results from the study HBSC/WHO in Portuguese adolescents (Gaspar & Matos, 2008; Matos & Equipa Aventura Social, 2000-2014; Simões et al., 2014).

Adaptation to chronic diseases and individual perceptions have a dynamic and changeable course, and several moderators that interfere with this process have been recognized in research, namely gender, age and corresponding developmental levels (Barros, 2003; Holden, 1997; Taylor et al., 2008). In agreement with this tendency, such associations were also evidenced in the empirical studies 1 and 2 and this same direction previously pointed out in the literature, was found. In addition, the findings were in line with the literature supporting that mostly older adolescents (Piko, 2006) and girls (Currie et al., 2012; La Greca et al., 1995; Määttä et al., 2013) could be at high risk for more compromised psychological adjustment. This may be explained by the different internalization and externalization patterns (Marcotte, Fortin,

Potvin, & Papillon, 2002). Literature also depicted socioeconomic status as a significant moderator (Currie et al., 2012; Oishi et al., 1999; Olén et a., 2012) and, the reported outcomes in studies 1 and 2 followed the same path, with a low FAS/SES impacting life satisfaction and wellness perception. Also other studies in the literature (Cui et al., 2013; Mackenbach et al., 2008; Richter et al., 2009; Zashikhina & Hagglof, 2014), as well as previous ones conducted in Portugal (Gaspar & Matos, 2008; Matos & Equipa Aventura Social, 2000-2014) reported that a lower FAS/SES was associated with poorer life satisfaction, psychological health and QoL (Currie et al., 2012; Holden et al., 1997; Oishi et al., 1999; Olén et al., 2012; Taylor et al., 2008).

With respect to **socio-contextual** level, in family and school/peers' domains, the results of study 3 indicated that adolescents with chronic diseases reported poorer perception of satisfaction with family environment, higher levels of pressure with schoolwork and felt more frequently that their school competence was below average. Such results were in the same direction as pointed in research, suggesting that these adolescents may be at risk of high vulnerability, mainly in satisfaction with family environment (Michaud et al., 2007; Quittner et al., 2011), in school success (Bethel et al., 2012; Layte & McCrory, 2012), and potentially presenting poor self-perceptions of academic performance and perceived competence (Logan & Simons, 2010). In line with the literature (Currie et al., 2012; Holden et al., 1997; Oishi et al., 1999; Olén et al., 2012; Taylor et al., 2008), the same tendency observed in the individual-psychological levels for some influencing variables, was also found in study 3. Mostly girls (gender), older adolescents (age), and those who had a lower FAS/SES, were the ones at potentially higher risk. However, as for feeling pressure with schoolwork, a different direction reported that having a high FAS/SES and not having a chronic disease might be associated with feeling higher pressure, and for the perceived school performance, younger adolescents and the ones with higher FAS/SES reported a worse outcome.

The contextual results related to family may be explained if it is considered the literature that suggests that autonomy and independence from parents, and the start of connections with friends/peers' groups, are major relevant tasks in the developmental period of adolescence (Erickson, 1982; Sprinthall et al., 1998). However, in a situation of chronic disease, an adolescent might have his/her autonomy compromised. On the other hand, parents assume a difficult role of simultaneously protect and promote autonomy (Barros, 2009; Santos et al., 2013), thus, potential conflicts with parents are more likely to occur (Herzer et al., 2010; Nagano et al., 2010), and, this is more evident for older adolescents. Literature also suggested

that parental styles influence disease's control (Shorer et al., 2011) and may benefit general familiar functioning and better QoL in these adolescents (Botello-Harbaum et al., 2008; Monaghan et al., 2012).

Beyond the family context, the results found in school/peer's environment may be enlightened with evidence suggesting that adolescents with chronic disease can experience numerous school difficulties (Harris, Menard-Katcher, Atkins, Furuta & Klinnert, 2013), academic setbacks (Bethell et al., 2012) including truancy (Boonen & Petry, 2012) and impaired ability to cope with the demands of a classroom (Logan & Simons, 2010). In addition and according with the literature, these adolescents can also present a decreased readiness to learn, gaps in knowledge or low cognitive development (Layte & McCrory, 2012). Hence, poorer perceptions of school competence and pressure with schoolwork can influence a wide range of non-academic outcomes such as health, health behaviour and well-being (Currie et al., 2012). Furthermore, all of these drawbacks can potentially place adolescents with chronic disease at higher risk for poor educational, vocational and social outcomes in adulthood (Maslow et al., 2011). Although less significant for the general results, it was also observed that adolescents without chronic disease felt relevant pressure with schoolwork. This could be possibly explained, by the fact that parents tend to use less demanding educational tasks with the adolescents who have chronic disease (Ievers, Drotar, Dahms, Doershuk & Stern, 1994), and the youths, themselves, recognize that parents give those special privileges (Walker, Garber & Van Slyke, 1995).

Additionally, still in the peers' context, the results of study 4 indicated that adolescents with chronic disease reported more risky-internalizing behaviours, when compared with their healthy peers, who presented more healthy-behaviours. This findings are in line with previous studies that reported that adolescents with a chronic condition could be doubly disadvantaged and more vulnerable, engaging in risky-behaviours in a similar, if not higher rate, than their healthy peers (Blum, Kelly, & Ireland, 2001; Kakleas et al., 2009; Nylander et al., 2013; Sawyer et al., 2007; Saunders, 2011; Scaramuzza et al., 2010; Suris & Parera, 2005). The organization of these results in clusters is also in agreement with the literature that supports that healthy- and risky- behaviours tend to cluster together (Suris et al., 2008; DuRant et al., 1999; Rhee et al., 2007). Interestingly in these results, when gender was taken into account, the impact of disease on risk behaviours was revealed in a different way. Boys with chronic disease reported more

healthy-behaviours than healthy peers, who presented more risky-behaviours. In addition, boys whose attendance and participation in school was affected, reported more risky-behaviours, compared to the ones that were not affected and these did show more healthy-behaviours. Girls with chronic disease tended to present more internalizing behaviours and girls without a chronic disease, more healthy-behaviours. A possible hypothesis of interpretation can rely in the literature, that highlighted different internalization and externalization patterns (Cavallo et al., 2006), with girls usually presenting more internalizing behaviours, and boys more externalizing behaviours (Matos et al., 2012b,c; Suris et al., 1996; La Greca et al., 1995). In particular for boys, the apparent controversial results may anticipate that having a chronic disease may act as a protective factor, blocking their "natural" tendency for a more externalizing pattern of behaviour.

For the whole set of these four studies, and in agreement with the literature (Lee et al., 2013; Barros, 2009; Sawyer et al., 2002), results also revealed that outcomes could be more impacted when cumulative risks occurred together (Simões et al., 2014), such as having a chronic disease and additionally feeling that it affected participation and regular attendance at school. When this "double-match" situation occurs, data continue to show similar results, namely high vulnerability for all the previously discussed measures, *i.e.*, poorer perception of wellness, life satisfaction and satisfaction with family environment, as well as more internalized symptoms (such as depression), higher levels of pressure with schoolwork, feeling more frequently that school competence was below average, and reporting more risky-behaviours. It seems that when compared with healthy peers, the adolescents who have a chronic disease tended to report poorer outcomes, and, in addition, within the total group of chronically ill adolescents, feeling affected in school participation seemed to be an extra burden and an increased risk. On the other hand, not feeling affected can be hypothesized as a potentially protective factor for psychosocial functioning.

Overall, a higher vulnerability in both individual-psychological and socio-contextual levels was found in Portuguese adolescents with chronic diseases in a national-representative population sample. Variables that might influence outcomes, such as gender, age and SES (possible risk factors) stood out. However, specific data from chronically ill adolescents in a clinical context concerning HRQoL and psychosocial factors was still needed, and before that assessment, recent knowledge within the area was gathered and explained below.

2.2. Associations between Chronic Disease and the Impact on QoL, HRQoL and Psychosocial Factors in Adolescents*

* The present study was greatly benefited from the comments and kind assistance of Professor Dr. Joan-Carles Suris.

Globally, the findings of the systematic literature review (scientific study 5) evidenced associations between the impact of living with chronic disease and having a significantly higher risk of impairment of HRQoL/QoL (Alba et al., 2013; Cortina et al., 2010; Elsenbruch, Schmid, Lutz, Geers, & Schara, 2013; Haverman et al., 2012; Herzer, Denson, Baldassano, & Hommel, 2011; Mellion et al., 2014; Moreira et al., 2013; Olsen et al., 2012; Vanhalst et al., 2013; Wang, Wang, Wang, & Xu, & Zhang, 2012), psychological functioning (Cortina et al., 2010; Moreira et al, 2013; Vanhalst et al., 2013, Williams et al., 2013) and social functioning (Carona et al., 2014; Vanhalst et al., 2013). Such findings follow the direction already described in previous literature (Compas et al., 2012; Kourkoutas et al., 2010; Payot & Barrington, 2011; Petersen-Ewert et al., 2011; Varni et al., 2007). Nevertheless, other review studies presented controversial results, namely *no significant differences* (Elsenbruch, Schmid, Lutz, Geers, & Schara, 2013; Velasco Martín, Díez, Pérez, & Amigo, 2012, Vetter, Bridgewater, & Jr, 2012), and *significant lower risk* of impairment (Andres et al., 2014; Békési et al., 2011; Rassart et al., 2012; Zashikhina & Hagglof, 2014). The reported satisfactory, or even moderate to high outcomes found, could be explained by reported protective factors, mainly social dimensions/peer relationships (for example in diabetes *mellitus*), but also gender, lower disease severity and higher socio-economic status (e.g. in asthma and epilepsy). Additionally, the need to "fit with peers" or the denial of disease-related problems may also have resulted in favorable social responses in self-reports (Rassart et al. 2012; Velasco et al., 2012).

Such heterogeneity and controversial results found in the review studies can be explained taking into account that adaptation responses to chronic disease are heterogeneous and quite variable, depending on individual and contextual factors (Lee et al., 2013). In addition, disparities may derive from the diverse definitions of chronic diseases (including various health conditions and degrees of severity), and the varied instruments used to assess HRQoL/QoL and psychosocial factors, despite the efforts to organize the information within this area, in the last years (Varni et al., 2007; van der Lee, 2007, Mokkink et al., 2008).

Regardless of controversial findings, disease-specific factors such as physical ability, pain, subjective burden of medication use (Haverman et al., 2012), diagnosis (Békési et al., 2011; Herzer et al., 2011; Wang et al., 2012; Zashikhina & Hagloff, 2014), severity of the disease (Mellion et al., 2014; Vanhalst et al., 2013; Zashikhina & Hagloff, 2014), school absence (Cortina et al., 2010; Haverman et al., 2012), and illness perception (Williams et al., 2013), were identified as relevant for HRQoL. On the other hand, non-disease factors, namely anxiety/depression (Velasco et al., 2012), age (Alba et al., 2013; Moreira et al., 2013; Zashikhina & Hagloff, 2014), socioeconomic status (Herzer et al., 2011; Zashikhina & Hagloff, 2014), quality of peer relationship (Rassart et al., 2012), social interaction/social support (Békési et al., 2011; Carona et al., 2014; Elsenbruch et al., 2013; Vanhalst et al., 2013), parents support (Békési et al., 2011; Williams et al., 2013) and gender (Rassart et al., 2012; Williams et al., 2013; Zashikhina & Hagloff, 2014) also showed to be crucial predictors. Generally, social support (from peers and parents), peer relationship and mental health (taking into account gender and age differences) were particularly stressed out in the review.

Regarding gender in particular, the review studies underlined a tendency for girls, when compared to boys, to report higher risk in various domains, namely in QoL and disease-related concerns (Zashikhina & Hagglof, 2014), psychological symptoms (depression and anxiety) (Williams et al., 2013) and life satisfaction. However, in social dimensions, girls reported higher peer relationship quality (Rassart et al., 2012), physical/social HRQoL's dimensions (Alba et al., 2013) and less externalizing problems (Carona et al., 2014) than boys.

The conducted systematic review also showed that wide age ranges were mostly employed and only some studies focused on the specific adolescent's developmental stage (Herzer et al., 2011, Olsen et al., 2012; Rassart et al., 2012; Vanhalst et al., 2013; Wang et al., 2012; Williams et al., 2013; Zashikhina & Hagglof, 2014). Therefore, this evidence may foresee difficulties in isolating this specific age and a considerable inconsistent approach to age group specificities, in agreement with the literature (Carona et al., 2015a; Sawyer et al., 2007; Varni et al., 2007). Moreover, it was also reported that age could be a possible risk factor for maladjustment with worse outcomes for older adolescents (Békési et al., 2011; Moreira et al., 2013), which was to be expected considering that they live a complex period of their lives, where several unique transformations take place, namely the urge for personal identity, autonomy and independence) (Carona et al. 2013).

Finally, literature review highlighted the need to routinely assess HRQoL and psychosocial factors and to focus more on subjective health parameters, on the perception of limitations in daily activities and less on physical/objective health parameters (Vanhalst et al., 2013) that are more difficult to change. Furthermore, it suggested to adopt an individualized framework, to considerer adolescents as a single/independent group and to emphasize potentially protective/risk factors, suggesting that these can all be possible directions to enable multidisciplinary interventions, in order to improve HRQoL and psychosocial care in this age group (Békési et al., 2011, Elsenbruch et al., 2013; Mellion et al., 2014; Zashikhina & Hagglof, 2014).

These recommendations follow the same directions comprised in The Ottawa Charter (WHO, 1986) for health promotion, suggesting the need to develop personal skills and to enable people to increase control over and improve their health, as well as in the common policy priorities for Health 2020 (WHO, 2013b), stressing out the need to empower people and create resilient communities. These data also agree with the recommendations to evaluate QoL in children and adolescents with self-reports (whenever possible) and developmental appropriate measures (WHO, 1993), and with the Global Action Plan for Non-communicable Diseases (NCD), which proposed to focus on the underlying social determinants through people-centred primary health care and universal health coverage (WHO, 1993; 2014a,b).

2.3. Impact of Chronic Disease on HRQoL and Psychosocial Factors in a Clinical Population of Portuguese Adolescents*

* The present studies were greatly benefited by the cooperation with the Paediatrics Department of *Hospital de Santa Maria*, CAML, with all the health professionals in the Outpatient Department, and the adolescents and parents who kindly participated.

Categorical Approach - More Similar than Different? (empirical study 6)

In study 6, the three groups of diseases (diabetes *mellitus*, allergic diseases and neurological diseases) presented no differences on HRQoL, psychosomatic health, resilience and social support. These findings are opposite to studies indicating differences between chronic diseases (Mellion et al., 2014; Moreira et al., 2013; Wang et al., 2012), but in accordance with others not confirming a direct relationship between the degree of suffering and the clinical condition (in comparisons of adolescents with different diseases) (Combs-Orme et

al., 2002; Villarreal-Rodríguez et al., 2013; Leung et al., 1997). These results were somehow expected taking into account the literature evidence that different paediatric chronic diseases have several features in common, and the psychosocial consequences of chronic disease tend to be similar across nosological categories (Stein & Jessop, 1982), that is the designated non-categorical approach (based on the burden of disease severity, and not on the specific diagnosis) (Stein et al., 1993; Sawyer et al., 2007a; Varni, 1983). Therefore, literature pointed out that little is lost by combining apparently distinct chronic diseases due to the great commonality in their psychosocial implications (Pless & Perrin, 1985; Varni & Wallander, 1989).

Two exceptions were found in the results of study 6 concerning differences in the groups of diseases. First, adolescents with diabetes *mellitus* presented slightly higher general and short-term self-regulation (minor significance), as well as the ones using special equipment (which were mostly the adolescents with diabetes mellitus, 97.7%). Such result is in line with literature that indicated that these adolescents must adhere to multiple complex daily tasks, which imply training and getting used to, and may probably contribute to higher levels of self-management, associated to a better metabolic control in youth (Chao, Whittemore, Minges, Murphy & Grey, 2014). Second, adolescents with neurological diseases reported slightly worse psychosomatic health with multiple complaints (minor significance). This is also in agreement with prior studies pointing out that having a greater number of health problems (3 or more compared with 2) (Barros, 2009; Lee et al., 2013; Sawyer et al., 2002; Simões et al., 2014) can lead to worse responses. Additionally, such group of diseases are probably the ones with higher visible limitations, and research identified it as relevant to primarily determine the adolescent's perception of the diseases' severity (Leung et al., 1997).

Overall, these findings concord with the evidence that disease activity may not be associated to psychosocial factors and fails to reveal the self-perceived QoL of adolescents (Sawyer et al, 2002; Kojima et al., 2009), thus, further analyses on adolescents were needed. Based on the literature, and on the requirement for a larger sample with reasonable power for multivariate procedures, diagnostic groups were combined and a non-categorical approach was assumed. The consequent studies are explained below.

Non-categorical Approach: More Different than Similar? (empirical studies 6-9)

- ***General HRQoL and Psychosocial Functioning (study 6):***

  In the total group of adolescents, a relatively moderate to high levels of HRQoL and social support were found. These results are in the opposite direction to studies showing a high risk of impairment (Alba et al., 2013; Mellion et al., 2014; Moreira et al., 2013; Olsen et al., 2012; Vanhalst et al., 2013; Velasco et al., 2012). However, they are in agreement with others reporting lower risk of impairment (Andres et al., 2014; Békési et al., 2011; Rassart et al., 2012; Zashikhina & Hagglof, 2014), evidencing a reasonable psychosocially functioning, general well-adjustment, and less severe diseases self-perception than physicians did (Leung et al., 1997). These findings are also similar with previous studies showing that the majority of these adolescents are satisfied with their personal and social lives (Denny et al., 2014), and follow a similar tendency observed in Portuguese data (Matos & Equipa Aventura Social, 2006; Matos et al., 2012b). Such ambiguity of results was previously discussed in the systematic review and it is a common feature in chronic disease's field, due to a heterogeneity of definitions and measures.

  The results of study 6 may possibly be explained considering the fact that when assessing QoL, aspects of the disease and its limitations are sometimes underestimated. Disease interferes with adolescent's experiences and their psychosocial perceptions, but it can, at the same time, promote personal maturity. Thus, an interaction and reciprocal potential effects between disease and developmental processes have been indicated in research (Suris et al., 2004). In addition, research also considered that developmental needs are possibly the same for both, healthy and chronically ill adolescents, implying the existence of a similar structure of QoL in such population, since health, physical and mental well-being are crucial dimensions (Olés, 2014). Furthermore, another hypothesis is the need to "fit with peers", the denial of disease-related problems and consequent social responses in self-reported questionnaires (Rassart et al., 2012; Velasco et al., 2012), as well as the presence of potentially protective factors, such as social dimensions, gender and lower disease severity. It was observed in this population that the majority of the adolescents did not feel affected by the disease in their school/social participation and also presented a moderate/high social support. Considering that feeling affected in school was a potential risk factor (from previous findings in HBSC studies and from the literature pointing less severity of the disease), and

that social support is linked to HRQoL (both directly and indirectly *via* internalizing and externalizing problems) (Carona et al.. 2014), these can be additional explanations for such results and suggested as potentially protective factors for HRQoL' outcomes. Nevertheless, moderate to high results in HRQoL may not fully indicate a successful adaptation or the daily efforts and challenges that these adolescents have to face (Denny et al., 2014; Nylander et al., 2013), and a focus on protective factors was needed

Facing the fact that various explanations can exist, additional analysis were needed to better understand such associations and to address if HRQoL and psychosocial factors were affected by chronic disease in a different way. This was the particular case when considering influencing variables, such as gender, and feeling affected in school/social participation (disease severity proxy); both are explained below.

- ***Comparisons between disease affecting/not affecting school and social participation (study 7):***

  Despite the fact that the majority of the adolescents reported not feeling affected by chronic disease in their school participation and regular attendance at school (PSCH), nor in leisure time with friends (PLTF), the results of this study evidenced a substantial number of other youths expressing that disease affected school and social participation, 13-18% respectively. Comparisons among these two groups showed that adolescents who felt affected in school/social participation tended to report lower HRQoL, poorer psychosomatic health, worse resilience, lower self-regulation competences, and less social support, when compared to the youths that did not feel affected. These results match the literature that pointed out that the effects of living with a chronic disease in adolescence can be extended to other contexts (e.g., school and peer relationships), beyond the individual level (The KIDSCREEN Group Europe, 2006), resulting in a decreased participation in educational and social activities (WHO, 2002). Such results also emphasize previous studies demonstrating that in the presence of cumulative risks (e.g., having a chronic disease and feeling it affects school/social participation), the impact on adolescent's well-being (Simões et al., 2014) and QoL (Sawyer et al., 2002) can be stronger.

  These results also indicated that HRQoL, psychosomatic health, resilience, self-regulation and social support, were positively associated with adolescents not feeling that the disease

affected school participation. Yet, in an adjusted model by gender, age, socioeconomic status proxy and diagnosis, self-regulation and psychosomatic health were the variables with higher association, and they may be suggested as potential protective factors. Concerning self-regulation, literature has highlighted that living and adapting to a chronic disease involves adherence to multiple complex daily tasks, and all those demands require a high level of self-regulation in order to improve health outcomes (Chao et al., 2014). Therefore and as expected, the adolescents who reported higher self-regulation were more likely to feel not affected in their school/social participation, probably due to a better management of the disease. Previous research underlined that self-regulation can be related to disease management strategies and fundamental to reduce symptoms in most chronic diseases (Sattoe et al., 2015). Regarding psychosomatic health, previous research showed that worse outcomes (with more complaints) might represent an additional burden to chronically ill adolescents, along with their previous chronic disease (Suris et al., 2011). Hence, in the present results, having a higher psychosomatic health (with less complaints) is more likely associated with not feeling affected in school participation.

In addition, these results indicated that HRQoL, psychosomatic health, resilience, self-regulation and social support were associated with adolescents not feeling that the disease affected social participation. In an adjusted model by gender, age, socioeconomic status proxy and diagnosis, social support was the sole and most important variable explaining this association and it may be considered as another protective factor. These results are in accordance with the literature, which suggested that social support plays a crucial role (mostly in the presence of a chronic condition) (La Greca et al., 2012; Gaspar et al., 2012; Gaspar et al., 2009b; Sprinthall et al., 1998), connections with peers are key aspects for healthy youth (Békési et al., 2011; Maslow et al., 2012; Rassart et al., 2012), and participation in social activities can improve QoL.

Therefore, the group of adolescents who felt affected in their daily activities (namely school and social participation) may need more support while adapting to a chronic disease.

- ***Gender Differences (study 6 and 8):***

  Gender differences were observed (study 6) and boys reported a significantly higher HRQoL and less psychosomatic health (SCL), compared with girls. Such evidence is in line with

former studies pointing out that girls can be at higher risk for a more compromised psychological adjustment, reporting poorer health/mental health outcomes, multiple health complaints and more risk-internalizing behaviours (Currie et al., 2012; Määttä et al., 2013; Gaspar, Matos, Ribeiro, Leal, & Albergaria, 2014). After observing such gender differences using the instrument KIDSCREEN-10, a closer analysis to the role of gender was needed, specifically for the several dimensions of HRQoL, and its association with other psychosocial variables. For that purpose, another study was conducted using the KIDSCREEN-52 and consequently explained.

In study 8, results continued to show a relevant role of gender, now focused on several dimensions of HRQoL and in other psychosocial variables, and such results found support in previous research (Holden, 2007; Gaspar et al., 2012; The KIDSCREEN Group Europe, 2006; Ravens-Sieberer et al., 2001, 2005). Girls presented a poorer perception of HRQoL, with lower scores for the dimensions PHY, PBW, EMO, SEL, AUT, PAR and FIN, as well as worse psychosomatic health, when compared to boys. These findings depicting poorer outcomes for girls, go along with the previously reported in study 6, and are in line with the literature, both in chronically ill adolescents (Määttä et al., 2013; Suris et al., 1996; Williams et al., 2013; Zashikhina & Hagglof, 2014), and in general population (Currie et al., 2012; Gaspar et al., 2014; Marcotte et al., 2002; Matos, 2000-2014; Piko, 2006).

Interestingly, when controlling for school and social participation, the perception of HRQoL's dimensions was influenced in a different way by gender, and differences were revealed only for the boys and girls subgroups, although girls were still more affected by a poor HRQoL. Therefore, only in the boys' subgroup, psychosomatic health impacted the dimension PBW, self-regulation impacted SCH and resilience had a significant impact on the dimensions PBW, AUT, PAR and SOC. Only for the girls' subgroup, self-regulation impacted the dimension PHY, and, overall, for the psychosocial variables, social support seemed to be the most significant one. This findings agree with evidence in the literature showing that girls have higher levels of social support, peer relationships' quality, social functioning, less externalizing problems (Alba et al., 2013; Carona, 2014; Rassart et al., 2012), and they can share feelings more easily and seek support with peers and family. On the other hand but also in agreement with literature, boys tend to have more externalizing behaviours and adopt compensation ones, reacting though as if problems do not exist (Gaspar et al., 2012).

It is suggested that for girls, a safe and positive social environment is essential, whereas boys are more in need of interventions that could help developing personal competencies, such as self-regulation, symptoms control and mostly resilience internal assets, that can predict positive health outcomes and improve coping skills, in chronically ill adolescents (Gois et al., 2012; Hilliard et al., 2012; Helgeson et al., 2014; Matos et al., 2012a). Social support in particular can be considered as a strategic variable that can contribute to a good adaptation while facing potentially stressful new situations, because increases control and reduces tension (Gaspar et al., 2012).

After the findings in study 8 and considering the potential relevance of psychosocial factors also largely pointed out in the literature review, one more aim was still established, namely to enlighten the role of clinical and psychosocial variables (separated and combined) on HRQoL and psychosocial factors (explained below).

- ***Highlighting psychosocial variables (study 9)***

  Separately, both clinical and psychosocial variables had a significant association with the perception of HRQoL, showing moderate to high values of variance, 27.9% and 62.4% respectively. For the group of clinical variables, feeling affected in school/social participation and self-perceived pain were the most relevant, whereas for the group of psychosocial variables, psychosomatic health, resilience, self-regulation and social support were the most significant ones. These findings are in accordance with literature that indicates that perceptions of HRQoL can be influenced by several factors (The KIDSCREEN Group Europe, 2006; Ravens-Sieberer et al., 2001; 2005; Houtrow et al., 2012). They are also in line with previous suggestions focusing on reinforcing the importance to assess both disease related and non-disease-related factors (Sawyer et al., 2001), including physical, psychological and social perspectives (WHO, 2012), as well as limitations in ordinary activities (Denny et al., 2014; van der Lee et al., 2007). Interestingly, when combining the above identified clinical and psychosocial variables, a high value of explained variance was obtained (64.2%), but clinical variables were no longer significant and the psychosocial variables psychosomatic health, resilience and social support maintained their positive association with HRQoL's perception. To achieve such result, a different contribution from

both clinical and psychosocial variables was revealed: when first entering the clinical variables the variance only reaches 30% and much more from psychosocial variables seems to explain the total of 64.2%; inversely, when first integrating psychosocial variables, the clinical ones added a small significance to the model (0.6%). Such findings agree with a suggested dynamic interdependence between these different elements (Houtrow et al., 2012). Moreover, they follow the same line of evidence that emphasizes less the diagnostic categories/physical dimensions and more the disease's impact on psychosocial dimensions (Denny et al., 2014; Mackner et al., 2012; van der Lee et al., 2007). Lastly, they reinforce the previous results of study 8 and acknowledge the relevance of psychosocial dimensions, and also endorse the literature, highlighting the relevance of potently protective factors, more specifically, psychosomatic health (Suris et al., 2011), resilience (Guilera et al., 2015; Helgeson et al., 2014; Matos et al., 2012a), self-regulation (Gois et al., 2012) and social support (Békési et al., 2011; Wu, Geldhof, Roberts, Parikshak, & Amylon, 2013).

Chapter X
Study's Limitations and Strengths

1. Limitations

In the present study some methodological limitations were recognized and should be considered for the interpretation of the research findings, therefore, will be presented below.

1.1. Self-reported Bias

Research Phase I was entirely based on adolescents' self-reports (this is a widely-used procedure in a national survey design), and did not comprise proxy-reports from teachers. Research Phase III also did not included proxy-reports from parents, and relied on the singular adolescent's perspective. This was true also for the item concerning disease affecting participation in school and/or leisure time with friends. Therefore, unmeasured processes may have biased youth's perceptions.

Literature has frequently pointed out a *cross-informant inconsistency*, which consists of lack of agreement between both reports (Silva et al., 2015; Varni et al., 2000). More specifically, a *disability paradox* was suggested when maladjustment is greatly expected by external observers, though not verified, and even be contradicted in self-reports (Albrecht, & Devlieger, 1999; Carona et al., 2014). Such cross-informant variance port forward the need to access information concerning adolescents' chronic health conditions and its impact on their lives by asking them directly, since there is evidence that they can provide a better explanation of their own experiences (Mazur et al., 2013; Michaud et al., 2004; Sawyer et al., 2007a; Varni et al., 2005; Young et al., 2009). However, literature additionally suggests the inclusion of parent proxy-reports (multi-informant approach) together with self-reports (Carona et al., 2015; Van Roy et al., 2010), especially when the adolescent is unable or unwilling to make his/her own report (Varni et al., 2000).

Despite the possible self-reported bias, it is important to state that the instruments used were methodologically comprehensive to provide valuable insights (HBSC selected items in Research Phase I and the instruments used in Research Phase III, *vide* Part I-Introduction, Chapter V).

1.2. Causality Bias

In both Research Phases I and III, the cross-sectional design of the study precluded the inference of causality. This implies that the observed associations cannot be interpreted in a context of suggesting causal directions, and need to be considered more in terms of inter-relationships among the variables. Even relying in the directions suggested in the literature, with cross-sectional data, the directional paths assume that causal processes already occurred, and the system was at an equilibrium point (Kline, 2005).

The higher vulnerability observed on HRQoL and psychosocial variables among adolescents with chronic diseases might have been related with factors other than the chronic disease itself. However, the observed relations can reflect the effect that the disease may have on such variables. Literature has signaled an interaction and reciprocal effect of chronic disease and adolescence, because the disease can affect the developmental processes, but the opposite is also true, *i.e.*, physiological and psychological changes can also have an impact on the disease (Suris et al., 2004). Nevertheless, considering that relationships do exist between these variables, longitudinal studies should follow be conducted in order to investigate such associations over time.

1.3. Representativeness

In Research Phase III, participants were selected and approached directly by their health professionals (physicians and/or nurses) during medical appointments. This set of studies used a convenience (non-probabilistic) sample method, and a rather small population, resulting in limited representativeness and consequent generalization of the findings. Identification of the chronic disease was based on medical self-reported diagnosis, rather than with an objective assessment measure, thus potentially being a study limitation. An attempt to address this issue was conducted, including other clinical information in the self-reported questionnaire, such as time of diagnosis, disease-related use of special equipments and medication, self-perceived pain, and feelings that the disease affects participation in school (PSCH), and in leisure time with friends (PLTF) (these last two items considered as a disease severity's proxy).

Because only adolescents referred to one public hospital were included, and most of the mothers and fathers had a educational level (SES's proxy) between the 1st and 9th grades, respectively, a generalization of the results to other families with a hypothetical higher SES and in other public primary healthcare centers or private systems, is limited. In addition, due to the

group's heterogeneity (different diseases/impairments), the respective inclusion criteria applied and considering that most of these adolescents did not felt affected in the school participation nor in leisure time with friends, some adolescents were under-represented. Even when the majority reported not feeling affected in both areas, the observed outcomes frequently indicated that these variables concerning limitations in daily activities had a relevant association.

Inversely to Research Phase III studies, the ones from the HBSC Study (Research Phase I) did not have significant sample representativeness issues, because it was a nation-wide representative population and sampling was done in randomly selected clusters (schools and classrooms). In addition, the HBSC study followed a strict international protocol, where data collection and methodological procedures were obligatory for all participating countries, as well as revision and updating prior to each survey for quality assurance (Currie et al., 2012; Griebler et al., 2010; Roberts et al., 2009).

Notwithstanding the abovementioned limitations, this study provides major contributions that will be highlighted bellow.

2. Strengths

The present research work has several theoretical and methodological strengths that support the validity of results and allow a better understanding of the impact of living with chronic disease in Portuguese adolescents, specifically on HRQoL and psychosocial development. The aims of this work were conducted according to the literature, international guidelines within this area, and also sustained by well-established theoretical models, such as the Socio-Ecological Model of Human Development (Bronfenbrenner, 1977, 2005), the KIDSCREEN Model (The KIDSCREEN Group Europe, 2006) and the Disability-Stress-Coping Model (Varni & Wallander, 1988; Wallander et al., 1989).

At the empirical level, this study was strengthened by a thoughtfully selection of procedures and instruments. Research Phase I was greatly benefited from the HBSC standardized research protocol (Currie et al., 2012; Griebler et al., 2010; Roberts et al., 2009) and its application in the Portuguese context. Despite the fact that the used variables were developed post hoc from this existing survey, and consequently some of them only had a small

number of items, they were previously applied in other studies (Matos & Equipa Aventura Social, 2000-2014; Matos et al., 2012c, Matos et al., 2015).

In Research Phase III a more comprehensive and multi-dimensional approach was adopted for a better explanation of the differential psychosocial outcomes (Wallander et al., 1988, Wallander et al., 1989). Measures such as psychosomatic health, resilience, self-regulation and social support were comprised, in an attempt to move away from frameworks mostly based on deficits, and emphasize possible protective factors and "health assets" identified as possible predictors of health outcomes (Barlow & Ellard, 2006; Morgan & Ziglio, 2007). Additionally, self-reported questionnaires were used, in agreement with the literature recommendations (von Mackensen et al., 2013; WHO, 1993), and also taking into account the health psychological framework (Barros, 2003), that emphasizes the adolescent's subjective perspectives and experiences (Barros, 2003).

Finally, the most important aspect of this thesis is to, altogether and through the vision of two self-reported informants (HBSC and clinical-specific context), enabling a better understanding of how adolescents experience living with chronic disease. The present findings give important contributions in a relevant current topic and worldwide health concern, due to the increasing numbers of chronic diseases in adolescence in the last decades, which will most likely tend to continue. Moreover, the empirical results enlightened youths' needs and potential protective factors, that might allow a better planning of future specific interventions to help the ones who struggle with chronic diseases, and to improve psychosocial care in adolescents.

Overall, this study brings key contributions. First, an important national epidemiological overview and information regarding the psychosocial development of young people with chronic diseases. Second, a specific overlook of the impact of living with chronic disease in a clinical population of chronically ill adolescents. In both contexts the results observed may help to identify possible adolescents who require greater psychosocial support. Such knowledge is necessary to design actions that focus on the reduction of disease's potential impact and improving the surrounding contexts where adolescents develop.

The present findings do encourage future research, and improve awareness on clinical practice and health policies, both highlighted in the next chapter.

Chapter XI
Theoretical Implications and Future Directions

1. Implications for Future Research

The present research provided new visions about the impact of chronic disease on HRQoL and psychosocial development of adolescents at a certain point in time. Based on the previously discussed results and methodological considerations, further studies are required. Indeed, several promising possibilities can be considered to explore in the future, focused not only on specific environments, but also on the global level, and including not only the paediatric context, but also schools and the entire society.

Replication and Generalization (specifically for the clinical context). It would be important to replicate the observed associations in larger populations in order to increase representativeness of the different chronic diseases under-represented in these set of studies. It would also be relevant to include other populations with different socioeconomic status, from different geographical regions and other public/private hospitals and primary care healthcare centers. This would increase statistical power and allow for more complex statistical analyses. In this process, the importance of having more homogeneous sample characteristics and to continue to use a multi-dimensional assessment of QoL (including physical, psychological and social dimensions of functioning) is underlined Wallander et al., 1988, Wallander et al., 1989). In addition, it would also be fundamental to clarify the potential role of protective factors, such as psychosomatic health, resilience, self-regulation and social support, and to explore possible reciprocal influences.

It will be relevant to further explore comparisons with the HBSC national-representative study that includes both groups of healthy and chronically ill adolescents, with a larger sample, to better understand potentially contextual-influencing variables. Lastly, to explore the association with other psychosocial variables related to healthy and active life styles is pertinent, because most of chronic diseases in adolescence are not preventable with lifestyle changes but many co-morbidities should be highly modifiable (Sawyer et al., 2007a). Moreover, because there is evidence that healthy/risky-behaviours tend to cluster together, and

adolescents with chronic diseases may be doubly disadvantaged, due to the adverse consequences of risk behaviours (Saunders, 2011; Suris et al., 2008).

Multi-informant Approach (specifically for the clinical context). It consists of complementing adolescent's self-perceptions with HRQoL's proxy-reports from parents, through a multi-informant approach (Carona et al., 2015; Van Roy et al., 2010). Despite the frequent *cross-informant inconsistency* reported in the literature (Silva et al., 2015b; Verhulst & van der Ende, 1992; Youngblade & Shenkman, 2003), it would be useful to clarify specific paths explaining the associations between both reports, because having agreement or and/or disagreement might compromise the relationship of parents and adolescents. This is particularly relevant in the period of adolescence where the need of independence from parents, and more social contact with peers and friends, start to increase.

Focus on Adolescents. Studies should focus specifically in adolescents; indeed, literature reports a substantial difficulty to assess and consider this age period as independently from others with developmental specific needs (Carona et al., 2015; Erickson, 1982; Sprinthall et al., 1998; Varni et al., 2007). This is also particularly relevant considering the typical developmental tasks within this age (autonomy, independence), and the consequent extra burden for adolescents who live with a chronic disease.

Mixed-method Procedures. To implement a mixed-method procedure (Creswell, 2009), combining both quantitative and qualitative data. Literature has suggested that qualitative research (e.g. interviews, focus groups) may be a promising way to better "listen to the voice" of adolescents and to their needs (Fegran et al., 2014; Michaud et al., 2004; Varni et al., 2005; Zhang & Creswell, 2013), and to further understand relevant individual experiences and processes that may predict outcomes. Qualitative methods can enlighten for example, the main reasons for adolescents feeling/not feeling affected in school and in social participation, as well as to discuss problem-solving solutions.

Longitudinal Studies and Case-control Studies. These studies should be conduct since the link between living with chronic condition in adolescence, and the direct effects on psychosocial health appears to be very complex and wider effects have not been systematically studied. Literature indicates scarce longitudinal studies trying to identify the effects of social, economic, educational and pubertal transitions on health outcomes and risk behaviours (and *vice-versa*), in young people with chronic diseases and disabilities (Sawyer et al., 2007a). Such studies could provide stronger inferences and causal directionality, focusing on relevant aspects

that can bring bias on the results, such as the identification of individual adolescent's protective/risk psychosocial factors, adaptation processes and the moment of the diagnosis (early childhood – hypothesis of better adaptation *vs.* late in adolescence).

This methodological approach is also crucial to explore the association through the disease course across adolescent's developmental stages and family cycles. However, it is recognized that longitudinal studies are expensive and the country is currently facing economic constraints. One way to address this, particularly referring to the HBSC study (because it is conducted every 4 years), consists of repeating cross-sectional analyses using other time-points. This would allow further monitoring of the impact of chronic disease in young people's psychosocial health. During the present research new insights were added to the *Chronic Condition Optional Package* of the Portuguese HBSC survey in 2014, such as the inclusion of items concerning the self-perceived limitations in daily tasks/surrounding environments. This work is still on progress with scientific discussions within the *Chronic Condition Writing Group*, in order to improve the items for the 2018 survey. Preliminary results of 2014 data can be consulted in Part IV-Annexes, Chapter XVI (but are not in discussion in the present thesis).

Evaluation of Interventions. The implementation of psychosocial interventions is extremely important, but also its cost-effectiveness evaluation, thus, such procedure is highly recommended. Moreover, because the literature has underlined a generally lack of empirical evidence-based outcomes (Martiniuk, 2003).

2. Healthier and Wealthier Adolescents: Contributions for Clinical Practice and Health/Education Policies

In the last section of this thesis some suggestions that may contribute to improve clinical practice and health care policies will be presented and discussed. Such considerations resulted from extensive literature review, international recommendations and guidelines, connection with other national/international expertise and discussion of the empirical studies. This contributions also follow the goal of the HBSC study, specifically in disseminating findings to researchers, health and education policy makers and health promotion practitioners, school

staff, parents, young people and other relevant audiences, in order to better promote health and prevent risk behaviours (HBSC, 2014; Matos & Equipa Aventura Social, 2000-2014).

These contributions also rely on the golden rules of health psychology and paediatric psychology that focus on protection/promotion of health and prevention/treatment of diseases (Ribeiro, 2006; Leal, 2006), based on a holistic perspective for disease management. Furthermore, they underline the relevance of strength-based approaches (Ribeiro, 2009; Seligman, & Csikszentmihalyi, 2000) and emphasize the necessary multi-disciplinary and collaborative work with paediatricians and other health professionals, in order to achieve brief though effective interventions (Barros, 2003; Michaud et al., 2004).

2.1. Integration of Psychosocial Assessment in Paediatric Healthcare

To routinely include psychosocial assessment in paediatric healthcare contexts assessing QoL, HRQoL and psychosocial factors, will allow a general evaluation of the burden that the disease might have on psychosocial dimensions, and not only on the disease-related ones (Vanhalst et al., 2013; Zashikhina & Hagglof, 2014). Additionally, it enables a multi-level perspective, comprising physical, psychological and social dimensions (Sawyer et al., 2997a; WHO, 2012). Therefore, such assessment has powerful practical applications because it combines an epidemiological perspective (population with/without chronic diseases), a political perspective (contributes to decision making in healthcare), and a clinical perspective as an outcome for interventions (Bullinger, 1997).

Focusing on a more clinical perspective, the inclusion of this routine assessment can bring various benefits, such as facilitating patient/paediatrician communication and shared decision-making, as well as the improvement of patient's satisfaction with medical care. In addition, it detects psychosocial and functional limitations ("hidden morbidities") (Varni et al., 2005). Furthermore, considering the reports in the literature of pronounced heterogeneity in outcomes related to the disease impact on HRQoL and psychosocial functioning (high risk/low risk/no significant differences on impairment) (Compas et al., 2012; Verhoof et al., 2012), an individualized assessment is also recommended. This will permit to identify for each adolescent/family their specific needs as well as risk/protection factors that can potentially compromise outcomes.

Screening measures in paediatric contexts should be brief, have a good reliability/validity, should be responsive to significant changes in the adolescent's health status,

and easily understood by patients, as well as easily interpreted and scored by paediatricians (Varni et al., 2005). A combination of both generic and disease-specific measures is recommended for a better comprehensive evaluation of QoL in clinical practice, allowing the conduction of intra- and inter-diseases comparisons, respectively (Sawyer et al., 2007a). Disease-specific measures convey increased knowledge of individual processes, whereas generic ones allow comparisons with different diseases and with population norms. Therefore, clarification of similarities and differences between specific diseases and groups of diseases could inform clinicians and health-care policies about models of adolescent-friendly health-care services, as reported in the literature (WHO, 2012). While considering a wider perspective of the health-care system, generic measures bring the additional advantage to provide wider information on physical, psychological and social domains of the adolescent functioning, along with the extensive life contexts that may result in additional risk for these youths (Silva, 2015). Therefore, models that transcend the specific condition may be especially valuable, because they report the common challenges for adolescents, parents and clinicians in the context of different diseases and may increase the effectiveness of available resources and supportive interventions (Sawyer et al., 2007a).

Notwithstanding the above mentioned arguments, this practice of psychosocial assessment is still poorly spread in Portugal healthcare services, probably due to the lack of reliable and valid measures adapted for the Portuguese population, due to the limited time of patients and health professionals for the its attendance (Silva, 2015), and probably due to some skepticism that does still exist regarding subjective self- and/or proxy-reported data (Spieth & Harris, 1996). In the specific Portuguese scenario, the generic instrument KIDSCREEN (Erhart et al., 2009; Gaspar & Matos, 2008; Ravens-Sieberer et al., 2010a; Ravens-Sieberer et al., 2010b) is a robust methodological option, as well as the DISABKIDS questionnaires (generic and disease-specific) (Carona, et al., 2013; Schmidt & Bullinger, 2003; Baars et al., 2005) (the last ones were not in the aim of the present thesis).

To use of self-reported assessments is another relevant issue in the paediatric setting with adolescents with chronic diseases, because it seems to facilitate the communication between adolescent/clinician and may increase the recognition of specific health care needs (Detmar, 2003), and an accurate report of symptoms or other daily limitations (Varni et al., 2005). This is also an excellent opportunity to give *"voice"* to adolescents (Sartain et al., 2000;

Young et al., 2009), because literature has evidenced that they are good interpreters of their world and do bring crucial information that can increase the knowledge on their individual process through the disease's adaptation, but also at a wider level in the health-care system (Mazur et al., 2013; von Mackensen et al., 2013). An additional study was conducted in the present research (but not in this thesis's discussion) concerning the satisfaction of adolescents with health-care services (*vide* Part IV – Chapter XVI).

Finally, because adaptation to chronic diseases is an individual process and changeable during time, it may be suggested that QoL and psychosocial functioning could be assessed on a regular basis, taking into account developmental stages and also changes in the course of the disease (e.g. clinical procedures, treatments). This is relevant considering that reciprocal effects were identified in previously research, and, if the disease can affect developmental processes, the opposite is also true, *i.e.*, physiological and psychological changes can also have an impact on the disease (Baptista, 2016; Suris et al., 2004).

2.2. Psychosocial Interventions in Adolescents with Chronic Diseases

The set of empirical studies and also previous literature suggested a potential role of protective factors, highlighting the relevance of age, gender and corresponding developmental levels (Määttä et al., 2013; Zashikhina & Hagglof, 2014), socioeconomic status (Currie et al., 2012; Oishi et al., 1999; Olén et al., 2012), feeling affected in school and social participation (Mellion et al., 2014; Simões et al., 2014; Vanhalst et al., 2013; Zashikhina & Hagloff, 2014), psychosomatic health (Suris et al., 2011), self-regulation (Gois et al., 2012), resilience (Guilera et al., 2015; Helgeson et al., 2014; Matos et al., 2012a) and social support (Békési et al., 2011; Wu, Geldhof, Roberts, Parikshak, & Amylon, 2013). Therefore, it may be suggested that while planning interventions, the inclusion of the above mentioned variables has to be taken into account. It is also proposed to implement inclusive interventions for adolescents with different chronic diseases that concurrently comprise individual and gender features, in order to increase intervention's effectiveness. Furthermore, WHO recommends an approach based on "health assets", which in relation to young people includes not only exploring individual skills such as resilience, but also community level attributes such as supportive social networks and strong intergenerational relationships (Morrow & Mayall, 2007).

There are already recommendations that may help to improve HRQoL and psychosocial functioning in adolescents with chronic diseases that will be presented below. It is additionally

underlined that a high amount of interventions rely on cognitive-behavioural techniques (CBT), because they have been widely recognized concerning their effectiveness in promoting more realistic assessments of successful events and in reducing symptoms in paediatric contexts (Eccleston, Palermo, Fisher & Law, 2012). Some of the most empirical evidence-based research in CBT interventions for paediatric health conditions is related to compliance to medical treatment regimens, pain management and social-cognitive problem solving (Varni et al., 2000).

Educational Programs are the most frequently applied interventions and rely on the assumption that an informed adolescent is more adapted, and has a better adherence to medical treatments. These programs reported a lack of empirical-based evidence and need to have individualized approaches, even in group based structures (Barros, 2003).

Self-management Programs have been reported in the literature and have been considered powerful to improve QoL and clinical outcomes (Tsai, Morton, Mangione, & Keeler, 2005). Research has underlined that an adolescent with effective self-management skills probably have greater self-care, and makes a better use of the professional's time (Lorig et al., 1999). It is suggested to educate and empower adolescents to manage as much as possible their own disease, along with empowering parents to gradually hand over the disease's management to them. In addition to the traditional information-giving and technical skills training (Sawyer et al., 2007b), education and coaching in problem-solving was also proposed in the literature, as well as relaxation and several techniques (such as self-control, self-instruction, self-desensitization and self-observation), are relevant for self-learning skills to better manage the disease (Barros, 2003). Although adolescents were participants in self-management support studies, age-specific analyses have not been done; therefore, cost-effective empirical evidence still lacks (Sawyer et al., 2007a). However, some studies have made an effort to give significant empirical-based outcomes and new concepts such as emotion regulation, started to be recognized (Dulak, Dymnicki, Taylor, Weissberg & Schellingr, 2011; Snyder et al., 2010). More recently, research has pointed out that the majority of European disease management programs does not address properly the multi-morbidity problem, and they skip on psychosocial and social environment support, as well as on addressing individual specificities and include decision-making engagement (Rijken et al, 2012).

The Promotion of Personal Competences such as self-regulation, symptoms' control and resilience, were also a focus for interventions and have been reported in the literature as relevant domains to promote a better adaptation and improve HRQoL (Gois et al., 2012; Hilliard et al., 2012; Helgeson et al., 2014; Matos et al., 2012a; Payot & Barrington, 2011; Suris et al., 2011). Levels of self-management are suggested for disease-related tasks (Chao et al., 2014), and the identification of irreversible aspects of chronic disease seems to help adolescents' resilience and adaptation to the new reality, improving well-being and HRQoL. This may foresee a universal psychological response to adversity proposing that adaptation requires a certain degree of acceptance (Payot & Barrington, 2011). Resilience frequently allows adaptation to adverse health states leading to better outcomes in HRQoL, but it has been observed that while facing challenges, some youth still struggle, while others do not. To learn practical and clinically relevant strategies from resilient adolescents can help planning psychosocial care for those that struggle (Hilliard et al., 2012), and resilience seems to be a promising candidate for interventions designed to reduce stress and improve outcomes (Guilera et al., 2015; Helgeson et al., 2014; Yi-Frazier et al., 2013). Although not in the specific field of chronic diseases, more recently in Portugal the importance of resilience has been acknowledge in interventions with children at an individual/family level (Pereira et al., 2015). Furthermore, a specific *curricula* focused on the promotion of resilience -RESCUR- has been recently developed and its inclusion in schools is recommended (http://aventurasocial.com/verartigo.php?article_id=268) (Cefai et al., 2014, 2015).

Social Support has been considered a strategic variable, contributing to a good adaptation while facing potentially stressful new situations, because it increases control and reduces tension (Gaspar et al., 2012). Therefore, social support programs have been pointed out in the literature, relying on the increasing importance of "face-to-face" peer support, and with various forms of implementation, whether school-based and disease-specific (e.g. Triple A-Adolescent Asthma Action), or community-based and generic (e.g. ChIPS-the Chronic Illness Peer Support Program) (Sawyer et al., 2007a). A recent systematic review comprised the most relevant Positive-Youth-Development (PYD) programs for adolescents with chronic diseases (Maslow & Chung, 2013), listed below:

- *TALC, The Adolescent Leadership Council* (USA): http://www.talcprogram.org/

- *Take Charge for your Future* (USA): http://cde.sagepub.com/content/24/1/89.abstract
- *Cool Friends, Befriending* (UK) http://www.qmu.ac.uk/hn/nursingresearch/docs/QNIS-Summary.pdf
- *Camp Ability* (USA) http://lifecenter.ric.org/index.php?tray=content&tid=top182&cid=5612
- *Triple A, Adolescent Asthma Action Program* (Australia) http://sydney.edu.au/medicine/public-health/salsa-triple-a/triple-a/index.php
- *Disease-specific programs for Diabetes* (Ireland) http://www.hse.ie/eng/services/Publications/topics/Diabetes/diabetesstructureded.pdf

The PYD perspective is a strength-based approach and emphasizes that a successful outcome in youths includes the development of competence, character, social connection, compassion and confidence. It considers youths as resources to be nurtured and focuses on the relation between youth's strengths and resources in the surrounding settings, as key to promote positive outcomes (Pittman, Irby, Tolman, Yohalem, & Ferber, 2011). Developing these positive attributes can promote self-care, better academic achievement, higher quality interpersonal relationships and overall improved well-being, not only in adolescence, but also in adult development and health care (Maslow & Chung, 2014). Effective PYD programs include: (1) youth participation: opportunities for youth participation and leadership of activities, (2) skill building: emphasis on the development of life skills; and (3) adult mentorship: a context of sustained and caring adult-youth relationships (Lerner et al., 2006). In Portugal, a Youth Lead Program for adolescents started in 2014 (*Dream Teens*, http://dreamteens.aventurasocial.com/) and although it is not specifically related to chronic diseases, it might bring relevant insights concerning methodological and procedure aspects for a possible future inclusion for these adolescents.

Summer Camping Programs are also commonly implemented as psychosocial interventions for youths with chronic diseases (Wu, Prout, Roberts, Parikshak, & Amylon, 2011). The goals of these programs tend to be comprehensive enough to address the common

needs of most youths, although comprising as well individual differences. The general aims include providing a fun and age appropriated experience, focused on activity-related skills, self-esteem, self-efficacy in peer relationships and educational information (informal way). However, a lack of evaluation was reported in this kind of interventions (Kiernan, Gormley, & MacLachlan, 2004), and some other studies have made an effort to provide empirical outcomes (Békési et al., 2011; Shepanski et al., 2005; Wu et al., 2011, 2013). An example of a specific summer camp for youth with chronic diseases is *The Bábar Tábor (Camp of Courage) Foundation* conducted in Hungary (http://www.batortabor.hu). Up to now, similar programs are scarce in Portugal; however, two associations that organize summer camps with adolescents are pointed out: the *Portuguese Association of Diabetes* and the *Portuguese Association of Youths with Diabetes* (http://www.apdp.pt/index.php/comunicacao/noticias/17-campo-de-ferias-da-apdp; http://www.ajdp.org/).

Programs focused on Transition to Adult Health Care have been frequently referred in the literature, and they integrate particular relevance for adolescents, due to their imminent entrance into adulthood. This issue has become an important topic and led to several recommendations (Castrejón, 2012; Kaufman et al., 2013; Michaud et al., 2004). Transitional care is defined as the medical assistance process by which a young chronically ill patient develops skills and resources for health care, during the transition from adolescence to adult life (Betz & Nehring, 2007). The notion of transitional to adult care is implicitly based on the need to improve young people's capacity to train and update several skills and competences. For that purpose, it was suggested taking into account the findings of the present empirical studies, for an individualized and early intervention. Once the difficulties seem to increase as children become older and have to deal with "being different" from peers, they simultaneously have to fight for autonomy from parents/adults, integrate a social group and rediscovery their body (and probably being even worse if they are girls and have a lower socioeconomic status). These early interventions might help adolescents to better accept the limitations imposed by chronic disease and readjusting life goals (Casier et al., 2011). An example of a specific program focused on transition to adult health care is the *On Your Own Feet (Opeigenbenen*) conducted in the Netherlands (http://www.opeigenbenen.nu/en/general/).

New Information and Communication Technologies have increased worldwide in the last decade and allowed to cross several barriers in a completely surprising direction and changed the paradigm of the typical adolescent tasks in the presence of a "new virtual world"

(Estefenon & Eisenstein, 2008; Santos & Matos, 2013). With such broad improvement in technology new possibilities emerged. Research has pointed out that people who make more health-related searches on the internet are precisely those with chronic diseases, those with more difficulties to access healthcare services, and the ones with lower social support (Bundorf, Wagner, Singer, & Baker, 2006; Lee & Hawkins, 2010; Tustin, 2010). In addition, adolescents use the internet frequently to obtain health-related information and health and chronic diseases have been reported as their main search topic (Ettel, Nathanson, Ettel, Wilson, & Meola, 2012). Thus, in the context of chronic disease, internet can be a potential help to reduce barriers to access traditional psychosocial interventions, such as the unavailability of professionals and issues concerning costs/time and regularity of attendance (Ritterband et al., 2003; Ritterband & Tate, 2009). Internet-based intervention programs and e-Health applications may significantly increase the access to care for an extensive number of adolescents and reduce geographical/economic barriers and health inequalities (Subrahmanyam & Šmahel, 2011). They also allow to maintain anonymity and bring additional advantages, such as higher flexibility and an earlier access to intervention compared with the traditional contexts (Proudfoot et al., 2011). Additionally, it is an opportunity to have educational information, establish social connections (in social networks) and to also contact with other adolescents experiencing similar situations (Santos & Matos, 2013).

Some internet-based programs have been reported in previous studies (McLean et al., 2010; Petrie, Perry, Broadbent, & Weinman, 2012; Suzuki & Beale, 2006), aiming to improve self-management skills and also cognitive changes (beliefs concerning disease/treatments), in order to maximize the effectiveness of cognitive-behavioural interventions in paediatric psychology (Barros, 2003). Recently, electronic games, television and music have been used as distractive techniques for pain-management, and disease- or generic- preventive programs can also be conducted through the internet (Stinson, Wilson, Gill, Yamada, & Holt, 2009; Webb, Joseph, Yardley, & Michie, 2010; Andersson, Ljótsson, & Weise, 2011).

Up until now, in Portugal and specifically in paediatric healthcare, internet-based programs focus on the improvement of HRQoL and psychosocial functioning in adolescents with chronic diseases is scarce. Nevertheless, due to a high rate of Portuguese people who use internet as a source of information (Santana, 2009) and the apparent readiness of health professionals (Moreira, 2012; Santana et al., 2010), it may be suggested as a promising and

inspiring tool to apply in the future. Therefore, to better provide psychosocial interventions for adolescents with chronic diseases, in a cost-effective way.

Finally, considering the high vulnerability within these adolescents in Portugal, the studies HBSC (Matos & Equipa Aventura Social, 2012b, 2012c, 2015) and KIDSCREEN (Gaspar & Matos, 2008), have been underlining the need to strengthen inherent support structures that can have a potential protective effect, such as **family** and **schools**, beyond the traditional health-care systems (Sawyer et al., 2007a).

Family as a whole, where parents assume the important role of caregivers (Barros, 2009; Fiese, Winter, Anbar, Howell, & Poltrock, 2008) is also affected by chronic disease, further than the individual level. Interventions towards the family empowerment could involve two perspectives. First, to provide medical care and establish a partnership between parents and clinicians, meeting their needs and preferences (King, King, Rosenbaum & Goffin, 1999). Second, to include psychosocial interventions, achieve positive family relationship and better adaptation outcomes (Fiese, 1997; Sawyer et al., 2001). Parental interventions should also provide key aspects on education (information and competence training), therapeutic needs (concerning parent's own emotions/experiences), and in organizational dimensions (centered on parent's social support needs). These goals can be achieved through parental education and intervention programs, individualized psychotherapeutic support and systemic/familiar therapy (Fine, 1991). In an context where adolescents frequently feel that their lives are ruled by the medical system, even in a family-approach intervention, it would be important to include their perspectives, and more specifically their suggestions to parents, such as learning better parenting styles, having greater confidence in their children, and gradually transferring to them the responsibility for medical treatment (Bregnballe, Schiøtz & Lomborg, 2011). Parents also seem to have an important role concerning school outcomes and parental encouragement can be considered to have a specific positive effect on adolescent health, beyond the effect of school environment and family communication addressed individually (Matos, Dadds & Barrett, 2006).

Interventions in **schools** can reduce the costs of special education services, may help adolescents to better control the disease and improve a healthy development into adulthood (Logan & Simons, 2010). Schools seem to offer an ideal setting where policies and *curricula* can influence students (Mercer et al., 2003) and might help reduce risk factors for chronic

disease, both in prevention (e.g. promoting healthy lifestyles) or disease management (O'Brien et al., 2010). Along with family, schools are a target group for interventions that may promote resilience and thus prevent possible health risky-behaviours (Nylander et al., 2013). While designing and implementing school-based intervention programs, it seems important to promote school "assets" as important features on school satisfaction and academic achievement for all, but in particular for the ones more vulnerable to achieve success (Simões et al., 2010a, 2010b). This is particularly relevant taking into account that in the present empirical studies it was observed an increased risk for the adolescents who had a chronic disease and additionally felt affected in school participation. Building competences in adolescents with chronic disease, strengthening connectedness and a better communication within the family, school, peer group and health care professionals, will enhance resilience and multiply opportunities to improve health outcomes in this population, creating support at school and in future professional career (Oeseburg et al., 2010).

Chapter XII
Conclusion

Even though the impact of chronic disease in adolescents' QoL/HRQoL and psychosocial functioning is a complex phenomenon, a large number of studies in the literature pinpointed a high impairment related to these variables. Nevertheless, many other studies have indicated lower risk or no significant differences. Therefore, literature hypothesized that those differences can be better explained by the heterogeneity of instruments and assessments, but also by potential protective factors and reciprocal effects between disease and developmental changes in adolescence.

The work conducted in the present thesis aimed to broaden the evidence on the associations between the impact of chronic disease on the QoL/HRQoL and psychosocial development of Portuguese adolescents, in a national-representative level and in a specific clinical healthcare setting. Overall, the set of findings provided indications that these young people experience a globally low HRQoL and psychosocial functioning. More specifically, the results allowed the identification of potential risk factors, such as age, gender and socioeconomic status. Within the group of chronically ill adolescents, limitations in daily activities (school and/or social participation) were frequently reported as an additional risk factor. Moreover, they also highlighted some possible protective psychosocial factors, such as psychosomatic health, resilience, self-regulation and social support.

This set of findings is important because QoL/HRQoL and psychosocial health, despite being generic/restrict constructs related to health and illness, are grounded on a wider definition of health (WHO, 1978), which states a fundamental common characteristic for all in terms of health and welfare. In addition, the results are also relevant because they inform about subgroups of adolescents with chronic diseases that are especially more vulnerable to poorer HRQoL and psychosocial outcomes, and such information is particularly useful for clinical practice and health/education policy makers. It provides pertinent suggestions for cost-effectiveness organization of available resources in existing services, and strengthens responses in the health-care system, focusing on psychosocial care.

In the light of the above mentioned, the present set of results strongly suggest that Portugal would benefit from considering the routine assessment and implementation of

interventions focused on QoL/HRQoL and psychosocial functioning in paediatric contexts, as a priority in the health agenda. Additionally, a better understanding of the reasons underneath why adolescents with chronic diseases feel affected in their daily activities should also be a priority in health and school's agendas, because with such information, actions to a significantly decrease risk factor for health outcomes could be achieved. Moreover, the inclusion of these procedures in health and school's agendas, using an individualized approach and self-reports, would allow to better listen to adolescents' "voices" concerning their specific needs. Providing pertinent knowledge for researchers and professionals to plan more effective changes and implement interventions, may lead to improvements in the psychosocial healthcare of these adolescents.

In a wider perspective, it would be an additional benefit to strengthen protective structures related to the adolescents' environment, with potentially cost-effective positive outcomes in the short- and in the long-term. Accomplishing these goals will require a coordinated action between all stakeholders: government, national entities, local municipalities, healthcare systems, health care professionals, schools, families, teachers, adolescents, peers, and community resources. Notwithstanding the national current financial constraints, it would be important to make efforts for an appropriate balance of available resources, in order to achieve such goals and to protect adolescents with chronic diseases who struggle. These are desirable assets of wealthy countries and developed societies, once the general investment on well-being of adolescents will have repercussions in adulthood, and for future generations.

The present set of findings are in line with available literature, emphasizing Sir Michael Marmot's idea that "even if conclusions are no different than before, it is important to be said again" (Marmot, 2012). Thus, this thesis' findings bring an additional challenge because in Portugal, up until now, the assessment of QoL/HRQoL in adolescents with chronic diseases is poorly spread and the existence of psychosocial-based intervention programs is scarce. The possible costs of inaction, in such crucial age period, may foresee that the direction of these findings will probably continue later in adulthood, in a cycle of cumulative consequences not only for the individual, but also for healthcare and societal systems. Thus, Portuguese researchers and clinicians may want to consider rethinking what has been done within this area, and to find more effective ways to implement previous knowledge into practice and into interventions that could indeed help these adolescents.

KEY-FINDINGS

- Overall, Portuguese adolescents with chronic diseases experienced a globally low HRQoL and psychosocial functioning;
- Influencing variables for lowering outcomes such as gender, age, socioeconomic status and feeling affected in school/social participation stood out; mostly the older adolescents, girls, those with lower socioeconomic status and feeling affected in school/social participation were reported to be at high risk of vunerability;
- The positive association of potential protective factors such as psychosomatic health, resilience, self-regulation and social support on HRQoL was highlighted;
- The routine assessment and implementation of interventions focused on QoL/HRQoL and psychosocial functioning in the specific age group of adolescence was recommended;
- An additional challenge for the Portuguese reality was pointed out, because up until now, the assessment of QoL/HRQoL in adolescents with chronic diseases is not common and the existence of psychosocial-based intervention programs is scarce.

Chapter XIII

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PART IV – ANNEXES

Chapter XIV

Phase I - Assessment Protocol

Annexe A -Ethical Approval from the HBSC/WHO

Due to the standardized international research protocol of the study HBSC/WHO, the digital version of the questionnaire cannot be presented. For further information it is suggested to contact with the Principal Investigator Professor Dr. Margarida Gaspar de Matos and the *Aventura Social* research team.

Parecer

Título do Projecto: "Aventura Social e Saúde – Estudo dos Comportamentos de Saúde em Crianças e Adolescentes em Idade Escolar".
HBSC/OMS (Health Behaviour in School-aged Children)
Nome do Investigador Principal: Margarida Gaspar de Matos
Serviço onde decorrerá o Estudo: Escolas do ensino regular, sob os auspícios da DGS e da OMS

Porto e H.S.João, 2013-12-23

O Presidente da CES

Doutor Filipe Almeida

CES
COMISSÃO DE ÉTICA PARA A SAÚDE

emitido na reunião plenária da CES de ___/___/___

Considerado que foram cumpridos os esclarecimentos prestados pelo requerido

A Comissão de Ética para a Saúde APROVA por unanimidade o parecer do Relator, pelo que nada tem a opor à realização deste projecto de investigação.

2013.12.23

Prof. Doutor Filipe Almeida
Presidente da Comissão de Ética

Chapter XV

Phase III - Assessment Protocol

Annexe A - Ethical Approval from the CHLN EPE

CENTRO HOSPITALAR LISBOA NORTE, EPE

HOSPITAL DE SANTA MARIA

Hospital Pulido Valente

Exma. Senhora
Dra. Teresa Cristina da Cruz Fatela dos Santos
Praceta Gago Coutinho, n.º 3 – 1º B
2660 – 441 SANTO ANTÓNIO DOS CAVALEIROS

Refª PCA – 12.NOV.2012 – 0785

Assunto: Projecto de Investigação "Qualidade de Vida, percepção de saúde, resiliência, auto-regulação e suporte social nos adolescentes portugueses com doença crónica".

Tenho o prazer de informar V. Exa. que o projecto de investigação em epígrafe foi aprovado pela Comissão de Ética para a Saúde do CHLN, e autorizado pelo Conselho de Administração em 8 de Novembro de 2012.

Com os melhores cumprimentos,

O Presidente do Conselho de Administração

Prof. Dr. J. A. Correia da Cunha

/MC

CONSELHO DE ADMINISTRAÇÃO

1

Av. Professor Egas Moniz
1649-035 LISBOA
Tel: 217 805 000 – Fax: 217 805 610
www.chln.pt

Alameda das Linhas de Torres, 117
1769-001 LISBOA
Tel: 217 548 000 – Fax: 217 548 215
www.chln.pt

Annexe B - Informed Consent for Parents/Caregivers

AUTORIZAÇÃO PAIS/ENCARREGADO DE EDUCAÇÂO

Por favor, antes de assinar, leia com atenção todo o conteúdo deste documento. Não hesite em solicitar mais informações ao investigador principal ou ao médico assistente se não estiver completamente esclarecido.

Convidamos o seu filho/a e respectivos pais e/ou EE para a participação de um estudo de investigação científica sobre *Qualidade de vida, percepção de saúde, resiliência, auto-regulação e suporte social nos adolescentes portugueses com doença crónica*. Esta investigação insere-se num projecto de doutoramento (Financiado pela FCT - Fundação Ciência e Tecnologia) em Ciências da Educação, Especialidade Educação para a Saúde da Faculdade de Motricidade Humana (UL), em colaboração com o Centro de Malária e Doenças Tropicais (IHMT/UL).

Porquê esta investigação?

A investigação realizada comparando jovens com doença crónica com jovens sem doença crónica (ou comparando com diferentes doenças entre si) tem sido contraditória e inconclusiva, não se confirmando relação directa entre doença e sofrimento/perturbação. A presente investigação tem como objectivo **compreender** e **avaliar** o **impacto** da **doença crónica** em **jovens adolescentes portugueses**, procurando identificar principais necessidades e prioridades, orientadoras de linhas estratégicas de intervenções mais eficazes para a melhoria da adaptação à doença crónica.

Em que consiste a participação?

A participação é **voluntária**, podendo a qualquer momento **desistir**, sem quaisquer consequências quanto aos direitos assistenciais. Ser-lhe-á solicitado a si o preenchimento de um questionário, e, ao seu filho/a, também o preenchimento de **questionários** (com dados demográficos e relativos a qualidade de vida, percepção de saúde, resiliência, auto-regulação e suporte social), e/ou a participação em sessões de Grupos Focais para discussão destas questões em grupo.

Vantagens de participar: a colaboração é fundamental para que possamos no futuro ajudar de forma mais eficaz outras crianças e jovens na adaptação à doença crónica. Simultaneamente, os resultados do projecto serão também divulgados junto da população inquirida através de relatório e/ou brochura informativa.

Custos e riscos: Não existirão custos associados, nem riscos associados à participação.

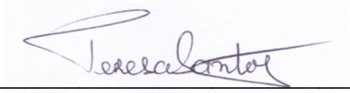
Anonimato/Confidencialidade: Todos os dados recolhidos serão tratados **confidencialmente**, sem o acesso de terceiros: o nome será substituído por um código, garantindo-se o **anonimato** através do acesso individualizado do investigador principal e equipa de investigação, à base de dados resultante. Os resultados poderão ser utilizados para publicação científica, mas apenas de uma forma global do grupo e não de um participante individual. O nome e contactos pessoais, serão utilizados pelo investigador principal e com o único objectivo de enviar informações relevantes no âmbito deste estudo..

Informação adicional: Se desejar informações adicionais, poderá entrar em contacto com Teresa Santos (investigadora principal, doutoranda) através do telefone: 21 4149199 ou por *email* para tsantos@fmh.utl.pt (www.aventurasocial.com).

Como colaborar: Se **autorizar a colaboração** do seu filho/a na presente investigação por favor **assine** a folha que se segue com o título: *Consentimento Informado* e entregue ao técnico responsável e/ou investigador principal.

Aspectos éticos considerados: anonimato, confidencialidade, liberdade de participar e desistência.

Agradecemos desde já o seu interesse e colaboração!
Em nome da equipa de investigação,

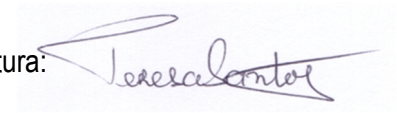


(Teresa Santos)

CONSENTIMENTO INFORMADO, LIVRE E ESCLARECIDO*:

A Equipa de Investigação declara: o encarregado de educação foi informado sobre o estudo, verbalmente e por escrito; os **dados fornecidos** serão utilizados apenas no âmbito deste estudo, assegurando-se a **confidencialidade e anonimato** dos mesmos; a **desistência não trará quaisquer consequências** para o utente e seus direitos assistenciais; a participação **não terá custos financeiros**.

Nome: Teresa Cristina da Cruz Fatela dos Santos
Função: Investigadora principal

Assinatura: 

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Annexe C - Informed Consent for Adolescents Older than 14 years old

AUTORIZAÇÃO CRIANÇAS/JOVENS

Por favor, antes de assinar, lê com atenção este documento. Não hesites em solicitar mais informações ao investigador principal ou ao médico assistente se não estiveres completamente esclarecido.

Convidamos a participar de um estudo de investigação científica sobre *Qualidade de vida, percepção de saúde, resiliência, auto-regulação e suporte social nos adolescentes portugueses com doença crónica*. Esta investigação insere-se num projecto de doutoramento (Financiado pela FCT - Fundação Ciência e Tecnologia) em Ciências da Educação, Especialidade Educação para a Saúde da Faculdade de Motricidade Humana (UL), em colaboração com o Centro de Malária e Doenças Tropicais (IHMT/UL).

Porquê esta investigação?
A presente investigação tem como objectivo **compreender** e **avaliar** o **impacto** da **doença crónica** em **jovens adolescentes portugueses**, procurando identificar principais necessidades e prioridades, orientadoras de linhas estratégicas de intervenções mais eficazes para a melhoria da adaptação à doença crónica.

Em que consiste a participação?
A participação é **voluntária** e terás que preencher um conjunto de **questionários** e/ou participar em sessões de Grupos Focais para discussão destas questões em grupo.

Vantagens de participar: no futuro, ajudar de forma mais eficaz outras crianças e jovens na adaptação à doença crónica. Simultaneamente, receberás os resultados do projecto através de relatório e/ou brochura informativa.

Custos e riscos: Não existirão custos associados, nem riscos associados à participação.

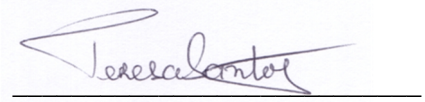
Anonimato/Confidencialidade: Todos os dados recolhidos serão tratados **confidencialmente**, o nome será substituído por um código, garantindo-se o **anonimato** através do acesso individualizado do investigador principal e equipa de investigação, à base de dados resultante. Os resultados poderão ser utilizados para publicação científica, mas apenas de uma forma global do grupo e não de um participante individual. O nome e contactos pessoais, serão utilizados pelo investigador principal e com o único objectivo de enviar informações relevantes no âmbito deste estudo..

Informação adicional: Para informações adicionais, poderás entrar em contacto com Teresa Santos (investigadora principal, doutoranda) através do telefone: 21 4149199 ou por *email* para tsantos@fmh.utl.pt (www.aventuralsocial.com).

Como colaborar: Assinar a folha que se segue com o título: *Consentimento Informado* e entregar ao técnico responsável e/ou investigador principal.

Aspectos éticos considerados: anonimato, confidencialidade, liberdade de participar e desistência.

Agradecemos desde já o teu interesse e colaboração!
Em nome da equipa de investigação,

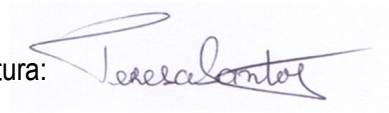


(Teresa Santos)

CONSENTIMENTO INFORMADO, LIVRE E ESCLARECIDO*:

A Equipa de Investigação declara: o utente foi informado sobre o estudo, verbalmente e por escrito; os **dados fornecidos** serão utilizados apenas no âmbito deste estudo, assegurando-se a **confidencialidade e anonimato** dos mesmos; a **desistência não trará quaisquer consequências** para o utente e seus direitos assistenciais; a participação **não terá custos financeiros**.

Nome: Teresa Cristina da Cruz Fatela dos Santos
Função: Investigadora principal

Assinatura: 

Data: ___/ ___/2013

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Annexe D – Questionnaire

Measures/corresponding Items:

- Socio-demographic Information (Items 1 to 11)
- Clinical Information (Items 12 to 17)
- Psychosomatic Health (SCL) - Symptom's Check List (Item 18)
- Self-Perceived Pain (Item 19)
- KIDSCREEN-52 (Item 20)
- KIDSCREEN10 (Items: 20.1.2, 20.1.5, 20.3.2, 20.3.6, 20.5.1, 20.5.5, 20.6.5, 20.8.3, 20.9.2, 20.9.4.)
- Resilience (RES) - Healthy Kids Resilience Assessment Module (Item 21)
- Self-regulation (SR) - Adolescent Self-Regulatory Inventory (Item 22)
- Social Support (SSSS) - Scale of Satisfaction with Social Support (Item 23)
- Additional information* (Items 24-29)

*(not in discussion in the present thesis, but used in supplemental publication related to this theme. Please see Chapter XVI).

Questionnaire:

Qualidade de vida, perceção de saúde, resiliência, autorregulação e suporte social nos adolescentes portugueses com doença crónica

AVENTURA SOCIAL — Faculty of Human Kinetics, Technical University of Lisbon — CMDT Centro de Malária e Doenças Tropicais Laboratório Associado — FCT Fundação para a Ciência e a Tecnologia

Instruções:

Por favor **lê todas as questões cuidadosamente** e lembra-te: isto não é um teste, por isso não existem respostas erradas. Algumas vezes para conseguires responder tens que escrever algo, noutras tens que escolher a resposta que está mais próxima da tua situação, colocando uma cruz na opção que consideras correta e que melhor te descreve.

Não penses muito sobre que opção deves escolher, pois a primeira ideia é geralmente a melhor. Não te preocupes se, às vezes, te enganares: basta riscares a resposta errada e, em seguida, colocares um círculo na opção que consideras correta.

Se tiveres alguma dúvida, levanta a mão e o investigador irá ajudar-te. Se existir uma questão que não consigas, mesmo, entender, por favor, coloca uma cruz à frente.

As tuas respostas às questões permanecerão anónimas, o que significa que nós não escreveremos o teu nome em nenhum local. Ninguém saberá o que respondeste.

Se te começares a sentir desconfortável relativamente ao que te é perguntado ou se não quiseres continuar a responder podes parar. Para isso, basta informares o investigador e ele recolherá o teu questionário.

Obrigada pela tua participação!

Data: ___/___/13 Nome: _____ Código: _____/____

1. És rapaz ou rapariga?

☐ Rapaz ☐ Rapariga

2. Quantos anos tens?

☐☐

3. Indica a tua data de nascimento:

_____(dia)/_____(mês)/_____(ano)

4. Localidade/Concelho: _____/_____

5. Escola: _____ **Ano/Turma:** _____

6. Quanto medes? .....cm **7. Quanto pesas?** ..... kg

(Se não tens a certeza tenta calcular o melhor que conseguires!)

8. Qual é a tua nacionalidade?

a) Portuguesa	☐
b) Angolana/Cabo-Verdiana/Guineense/Moçambicana/São-Tomense	☐
c) Brasileira	☐
d) Ucraniana/ Romena/ Moldava/ Russa	☐
e) Outra. Qual?_____	☐

9. Assinala todas as pessoas que moram contigo todo o tempo, ou a maior parte do tempo:

a) Mãe	Não	☐	Sim	☐
b) Pai	Não	☐	Sim	☐
c) Irmão e irmãs	Não	☐	Sim	☐
d) Outros familiares (sem ser irmãos)	Não	☐	Sim	☐

10. Qual o nível de instrução dos teus pais?

	PAI	*MÃE*		*PAI*	*MÃE*
a) Nunca estudou	☐	☐	d) Secundário (até ao 12º ano)	☐	☐
b) 1º Ciclo (até ao 4º ano)	☐	☐	e) Curso Superior	☐	☐
c) 2º/3º Ciclo (até 9º ano)	☐	☐	f) Formação Pós-graduada	☐	☐

11. Qual a profissão dos pais?

Pai: _____ Mãe: _____

12. Tens alguma doença prolongada, problema de saúde, incapacidade ou deficiência (tais como diabetes, artrite, alergia ou paralisia cerebral), que tenha sido diagnosticada por um médico?

a) Não ☐ b) Sim ☐

*Se **sim**, assinala qual:*

1) doença crónica – diabetes ☐ 2) doença crónica – asma ☐
3) doença crónica – epilepsia ☐ 4) doença crónica – doença cardíaca ☐
5) deficiência motora (ex: paralisia cerebral, deslocar-se em cadeira de rodas) ☐
6) deficiência sensorial (ex: problemas de audição, problemas de visão) ☐
7) outra (escreve qual): _____ ☐

13. Há quanto tempo tu ou os teus pais sabem que tens essa doença prolongada, problema de saúde, incapacidade ou deficiência (diagnosticada por um médico)?

a) Desde que eu nasci ☐ b) Durante a minha infância ☐ c) Há menos de 2 anos ☐

Obsv. (data diagnóstico): _____

14. Tomas algum medicamento para essa doença prolongada, problema de saúde, incapacidade ou deficiência?
a) Não ☐ b) Sim ☐ Qual? _____

15. Essa doença prolongada, problema de saúde, incapacidade ou deficiência faz com que tenhas de usar um equipamento especial (Por exemplo: canadianas, cadeira de rodas, caneta/bomba de insulina, glucómetro, aparelho auditivo, computador adaptado?
a) Não ☐ b) Sim ☐ Qual? _____

16. Essa doença prolongada, problema de saúde, incapacidade/deficiência afeta a tua assiduidade e participação na escola?
a) Não ☐ b) Sim ☐

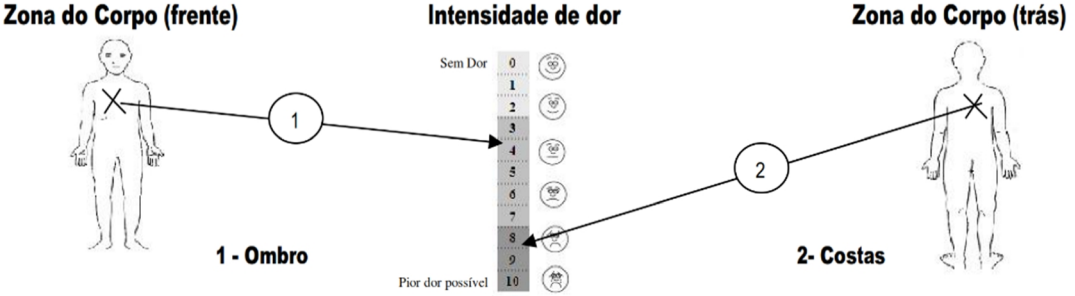
17. Essa doença prolongada, problema de saúde, incapacidade ou deficiência afeta a tua participação em atividades de tempos livre (com amigos, etc.)?
a) Não ☐ b) Sim ☐

18. Nos últimos 6 meses, com que frequência sentiste os seguintes sintomas, relacionados com a tua doença?
(Assinala uma resposta para cada linha).

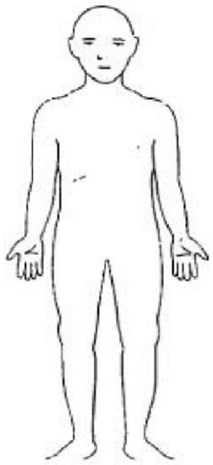
	Quase todos os dias	Mais do que uma vez por semana	Quase todas as semanas	Quase todos os meses	Raramente ou nunca
1) Dores de cabeça	☐	☐	☐	☐	☐
2) Dores de estômago	☐	☐	☐	☐	☐
3) Dores nas costas	☐	☐	☐	☐	☐
4) Estar triste/deprimido	☐	☐	☐	☐	☐
5) Estar irritado ou de mau humor	☐	☐	☐	☐	☐
6) Estar nervoso	☐	☐	☐	☐	☐
7) Dificuldades em adormecer	☐	☐	☐	☐	☐
8) Tonturas	☐	☐	☐	☐	☐
9) Dores de pescoço e ombros	☐	☐	☐	☐	☐
10) Medo	☐	☐	☐	☐	☐
11) Cansaço e exaustão	☐	☐	☐	☐	☐
12) Outro: _____	☐	☐	☐	☐	☐
13) Outro: _____	☐	☐	☐	☐	☐
14) Outro: _____	☐	☐	☐	☐	☐
15) Outro: _____	☐	☐	☐	☐	☐
16) Outro: _____	☐	☐	☐	☐	☐

19. Relativamente às duas últimas semanas e conforme o exemplo em baixo, assinala as zonas do corpo humano onde tens sentido mais dor com uma cruz (X) e a intensidade da dor, usando a escala de 1 a 10. Associa também cada seta ao nome da zona do corpo humano.

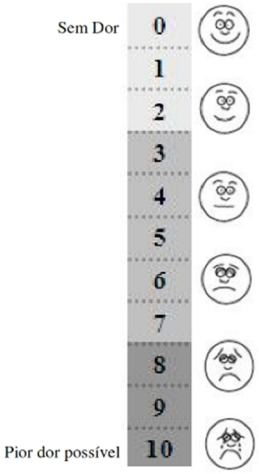
Exemplo:



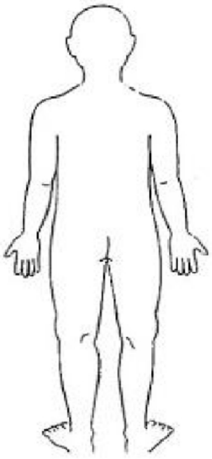
Zona do Corpo (frente)



Intensidade de dor



Zona do Corpo (trás)



20. Por favor pensa na tua última semana para responderes às questões seguintes, assinalando a que for mais adequada para ti com uma cruz (X).

20.1. Saúde e Atividade Física

	Muito má	Má	Boa	Muito boa	Excelente
1. Em geral, como descreves a tua saúde?	☐	☐	☐	☐	☐

Pensa na última semana	Nada	Pouco	Moderadamente	Muito	Totalmente
2. Sentiste-te bem e em forma?	☐	☐	☐	☐	☐
3. Estiveste fisicamente ativo(a) (ex: correste, fizeste escalada, andaste de bicicleta)?	☐	☐	☐	☐	☐
4. Foste capaz de correr bem?	☐	☐	☐	☐	☐

	Nunca	Raramente	Algumas Vezes	Frequente - mente	Sempre
5. Sentiste-te cheio(a) de energia?	☐	☐	☐	☐	☐

20.2. Sentimentos

Pensa na última semana...	Nada	Pouco	Moderadamente	Muito	Totalmente
1. A tua vida tem sido agradável?	☐	☐	☐	☐	☐
2. Sentiste-te bem por estar vivo(a)?	☐	☐	☐	☐	☐
3. Sentiste-te satisfeito(a) com a tua vida?	☐	☐	☐	☐	☐

	Nunca	Raramente	Algumas Vezes	Frequente - mente	Sempre
4. Estiveste de bom humor?	☐	☐	☐	☐	☐
5. Sentiste-te alegre?	☐	☐	☐	☐	☐
6. Divertiste-te?	☐	☐	☐	☐	☐

20. 3. Estado de humor geral

Pensa na última semana...	Nunca	Raramente	Algumas Vezes	Frequente - mente	Sempre
1. Sentiste que fizeste tudo mal?	☐	☐	☐	☐	☐
2. Sentiste-te triste?	☐	☐	☐	☐	☐
3. Sentiste-te tão mal que não quiseste fazer nada?	☐	☐	☐	☐	☐

	Nunca	Raramente	Algumas Vezes	Frequente - mente	Sempre
4. Sentiste que tudo na tua vida estava a correr mal?	☐	☐	☐	☐	☐
5. Sentiste-te farto(a)?	☐	☐	☐	☐	☐
6. Sentiste-te sozinho(a)?	☐	☐	☐	☐	☐
7. Sentiste-te debaixo de pressão ("stressado/a")?	☐	☐	☐	☐	☐

20. 4. Sobre ti próprio

Pensa na última semana...	Nunca	Raramente	Algumas Vezes	Frequente - mente	Sempre
1. Sentiste-te feliz com a tua maneira de ser?	☐	☐	☐	☐	☐
2. Sentiste-te contente com as tuas roupas?	☐	☐	☐	☐	☐
3. Sentiste-te preocupado(a) com a tua aparência?	☐	☐	☐	☐	☐
4. Sentiste inveja da aparência de outros rapazes e raparigas?	☐	☐	☐	☐	☐
5. Gostarias de mudar alguma coisa no teu corpo?	☐	☐	☐	☐	☐

20. 5. Tempo livre

Pensa na última semana...	Nunca	Raramente	Algumas Vezes	Frequente - mente	Sempre
1. Tiveste tempo suficiente para ti próprio(a)?	☐	☐	☐	☐	☐
2. Foste capaz de fazer atividades que gostas de fazer no teu tempo livre?	☐	☐	☐	☐	☐
3. Tiveste oportunidades suficientes para estar ao ar livre?	☐	☐	☐	☐	☐
4. Tiveste tempo suficiente para te encontrares com os teus amigos(as)?	☐	☐	☐	☐	☐
5. Foste capaz de escolher o que fazer no teu tempo livre?	☐	☐	☐	☐	☐

20. 6. Família, ambiente familiar e vizinhança

Pensa na última semana...	Nada	Pouco	Moderadamente	Muito	Totalmente
1. Os teus pais compreendem-te?	☐	☐	☐	☐	☐
2. Sentiste-te amado(a) pelos teus pais?	☐	☐	☐	☐	☐
	Nunca	**Raramente**	**Algumas Vezes**	**Frequente - mente**	**Sempre**
3. Sentiste-te feliz em casa?	☐	☐	☐	☐	☐
4. Os teus pais tiveram tempo suficiente para ti?	☐	☐	☐	☐	☐
5. Os teus pais trataram-te com justiça?	☐	☐	☐	☐	☐
6. Foste capaz de conversar com os teus pais quando quiseste?	☐	☐	☐	☐	☐

20. 7. Questões económicas

Pensa na última semana...	Nunca	Raramente	Algumas Vezes	Frequente - mente	Sempre
1. Tiveste dinheiro suficiente para fazer as mesmas actividades que os teus amigos(as)?	☐	☐	☐	☐	☐
2. Tiveste dinheiro suficiente para as tuas despesas?	☐	☐	☐	☐	☐
	Nada	**Pouco**	**Moderadamente**	**Muito**	**Totalmente**
3. Tiveste dinheiro suficiente para fazer atividades com os teus amigos(as)?	☐	☐	☐	☐	☐

20. 8. Amigos(as)

Pensa na última semana...	Nunca	Raramente	Algumas Vezes	Frequente - mente	Sempre
1. Passaste tempo com os teus amigos(as)?	☐	☐	☐	☐	☐
2. Fizeste atividades com outros rapazes e raparigas?	☐	☐	☐	☐	☐
3. Divertiste-te com os teus amigos(as)?	☐	☐	☐	☐	☐
4. Tu e os teus/tuas amigos(as) ajudaram-se uns aos outros?	☐	☐	☐	☐	☐
5. Sentiste-te capaz de falar sobre tudo com os teus/tuas amigos(as)?	☐	☐	☐	☐	☐
6. Sentiste que podes confiar nos(as) teus/tuas amigos(as)?	☐	☐	☐	☐	☐

20. 9. Ambiente escolar e aprendizagem

Pensa na última semana...	Nada	Pouco	Moderadamente	Muito	Totalmente
1. Sentiste-te feliz na escola?	☐	☐	☐	☐	☐
2. Foste bom/boa aluno(a) na escola?	☐	☐	☐	☐	☐
3. Sentiste-te satisfeito(a) com os teus professores?	☐	☐	☐	☐	☐
	Nunca	**Raramente**	**Algumas Vezes**	**Frequente - mente**	**Sempre**
4. Sentiste-te capaz de prestar atenção?	☐	☐	☐	☐	☐
5. Gostaste de ir à escola?	☐	☐	☐	☐	☐
6. Tiveste uma boa relação com os teus professores?	☐	☐	☐	☐	☐

20. 10. Provocação

Pensa na última semana...	Nunca	Raramente	Algumas Vezes	Frequente - mente	Sempre
1. Tens sentido medo de outros rapazes ou raparigas?	☐	☐	☐	☐	☐
2. Outros rapazes ou raparigas gozaram contigo?	☐	☐	☐	☐	☐
3. Outros rapazes ou raparigas provocaram-te?	☐	☐	☐	☐	☐

21. As seguintes afirmações são sobre a tua maneira de ser/personalidade. Lê cuidadosamente cada afirmação e assinala uma resposta para cada linha fazendo uma cruz (X) na coluna que melhor indica como te sentes.

	Totalmente falso	Um pouco certo	Bastante certo	Totalmente certo
a)... sinto-me triste quando vejo que outra pessoa sofre, porque alguém a magoou.	☐	☐	☐	☐
b)… tento compreender as dificuldades das outras pessoas.	☐	☐	☐	☐
c)… quando preciso de ajuda, encontro alguém com quem falar.	☐	☐	☐	☐
d)… eu sei onde posso encontrar ajuda quando tenho um problema	☐	☐	☐	☐
e)… tento resolver os problemas falando com alguém sobre eles.	☐	☐	☐	☐
f)… sou capaz de resolver os meus problemas.	☐	☐	☐	☐
g)... consigo fazer tudo, desde que tente.	☐	☐	☐	☐
h)… sou capaz de trabalhar com alguém que tem opiniões diferentes das minhas.	☐	☐	☐	☐
i)… há muitas coisas que faço bem.	☐	☐	☐	☐

	Totalmente falso	Um pouco certo	Bastante certo	Totalmente certo
j)… gosto de trabalhar em conjunto com outros alunos da minha idade.	☐	☐	☐	☐
k)… defendo os meus direitos sem ofender os outros.	☐	☐	☐	☐
l)… tento compreender como é que as outras pessoas pensam e sentem.	☐	☐	☐	☐
m)… a minha vida tem objetivos.	☐	☐	☐	☐
n)… compreendo a minha maneira de ser e os meus sentimentos.	☐	☐	☐	☐
o)… compreendo porque faço o que faço.	☐	☐	☐	☐
p)… tenho planos e objetivos para o meu futuro.	☐	☐	☐	☐

22. Lê cuidadosamente cada afirmação e assinala uma resposta para cada linha fazendo uma cruz (X) na coluna que melhor indica como te sentes.

	É Sempre Falso	Algumas Vezes é Falso	Não é Verdadeiro, nem Falso	Bastantes Vezes é Verdade	É Sempre verdade
1) É difícil perceber quando já cheguei ao "meu limite" (doces, comida, etc).	☐	☐	☐	☐	☐
2) Quando estou triste começo a fazer alguma coisa para me sentir melhor.	☐	☐	☐	☐	☐
3) Se alguma coisa não corre como planeado, consigo mudar o meu comportamento para tentar conseguir o que quero.	☐	☐	☐	☐	☐
4) Consigo concentrar-me no estudo, mesmo quando os meus amigos querem sair.	☐	☐	☐	☐	☐
5) Perco a noção do tempo quando estou a divertir-me.	☐	☐	☐	☐	☐
6) Quando estou aborrecido, fico irrequieto e não consigo ficar parado(a).	☐	☐	☐	☐	☐
7) É difícil iniciar grandes projetos que necessitam de muita preparação.	☐	☐	☐	☐	☐
8) Consigo agir naturalmente com as outras pessoas, mesmo quando estou zangado(a).	☐	☐	☐	☐	☐
9) Estou a par do que se passa à minha volta, mesmo quando estou em stresse.	☐	☐	☐	☐	☐
10) Quando tenho um dia difícil, consigo evitar queixar-me à minha família ou amigos.	☐	☐	☐	☐	☐
11) Mesmo quando já estou cansado, consigo iniciar uma nova tarefa.	☐	☐	☐	☐	☐
12) Perco o controlo quando as coisas não correm da forma que quero.	☐	☐	☐	☐	☐
13) Pequenos problemas distraem-me dos meus objectivos a longo prazo.	☐	☐	☐	☐	☐
14) Quando estou verdadeiramente a divertir-me, esqueço-me de todas as outras tarefas necessárias.	☐	☐	☐	☐	☐
15) Quando quero realmente alguma coisa, tenho que obtê-la imediatamente.	☐	☐	☐	☐	☐
16) Tenho dificuldade em prestar atenção durante uma aula pouco interessante.	☐	☐	☐	☐	☐
17) Quando me distraio ou sou interrompido, consigo facilmente voltar ao trabalho no ponto em que o deixei.	☐	☐	☐	☐	☐
18) É difícil manter a atenção no que estou a fazer, quando acontecem outras coisas à minha volta.	☐	☐	☐	☐	☐

	É Sempre Falso	Algumas Vezes é Falso	Não é Verdadeiro, nem Falso	Bastantes Vezes é Verdade	É Sempre verdade
19) Não tenho noção de quanto mais trabalho tenho pela frente.	☐	☐	☐	☐	☐
20) Quando me zango com alguém, consigo falar calmamente sobre isso, sem perder o controlo.	☐	☐	☐	☐	☐
21) Quando me sinto em stresse, é difícil começar a planear o que fazer perante um projeto ou problema.	☐	☐	☐	☐	☐
22) Consigo acalmar-me mesmo quando estou entusiasmado(a), ou quando determinada situação acabou.	☐	☐	☐	☐	☐
23) Consigo concentrar-me no trabalho, mesmo quando é aborrecido.	☐	☐	☐	☐	☐
24) Geralmente sei quando vou começar a chorar.	☐	☐	☐	☐	☐
25) Consigo evitar fazer certas coisas quando estou zangado(a), tais como atirar objetos.	☐	☐	☐	☐	☐
26) Trabalho cuidadosamente quando sei que o que vou fazer é complicado.	☐	☐	☐	☐	☐
27) Percebo os meus sentimentos antes de os demonstrar.	☐	☐	☐	☐	☐
28) Nas aulas consigo concentrar-me no trabalho, mesmo quando os meus colegas estão a falar.	☐	☐	☐	☐	☐
29) Quando estou animado(a) em atingir um objetivo (tirar boas notas, ganhar um jogo, etc) é fácil começar a trabalhar para isso.	☐	☐	☐	☐	☐
30) Consigo arranjar forma de manter os meus planos e objetivos, mesmo sendo difícil.	☐	☐	☐	☐	☐
31) Quando tenho um grande projeto, consigo manter-me a trabalhar nele.	☐	☐	☐	☐	☐
32) Consigo perceber quando estou a ficar cansado(a) ou frustrado(a).	☐	☐	☐	☐	☐
33) Deixo-me levar pelas emoções, quando me entusiasmo com alguma coisa.	☐	☐	☐	☐	☐
34) Quando estou realmente cansado(a), é difícil entusiasmar-me com alguma coisa muito especial.	☐	☐	☐	☐	☐
35) É difícil manter-me concentrado em alguma coisa que ache desagradável ou perturbadora.	☐	☐	☐	☐	☐
36) Quando sei que não devo fazer uma coisa, consigo resistir.	☐	☐	☐	☐	☐

23. Por favor, indica o grau em que cada uma das seguintes frases representa a tua maneira de pensar e ser. (Assin apenas uma resposta para cada linha.)

	Concordo totalmente	Concordo bastante	Nem concordo nem discordo	Discordo bastante	Discordo totalmente
1) Os amigos não me procuram tantas vezes quantas eu gostava.	☐	☐	☐	☐	☐
2) Estou satisfeito com a quantidade de amigos que tenho.	☐	☐	☐	☐	☐
3) Estou satisfeito com a quantidade de tempo que passo com os meus amigos.	☐	☐	☐	☐	☐
4) Estou satisfeito com as actividades e coisas que faço com o meu grupo de amigos.	☐	☐	☐	☐	☐

	Concordo totalmente	Concordo bastante	Nem concordo nem discordo	Discordo bastante	Discordo totalmente
5) Quando preciso de desabafar com alguém encontro facilmente amigos com quem o fazer.	☐	☐	☐	☐	☐
6) Mesmo nas situações mais embaraçosas, se precisar de apoio de emergência tenho várias pessoas a quem posso recorrer.	☐	☐	☐	☐	☐
7) Às vezes sinto falta de alguém verdadeiramente íntimo que me compreenda e com que possa desabafar sobre coisas íntimas.	☐	☐	☐	☐	☐
8) Estou satisfeito com a forma como me relaciono com a minha família.	☐	☐	☐	☐	☐
9) Estou satisfeito com a quantidade de tempo que passo com a minha família.	☐	☐	☐	☐	☐
10) Não estou com amigos tantas vezes quantas eu gostaria.	☐	☐	☐	☐	☐
11) Sinto falta de actividades sociais que me satisfaçam.	☐	☐	☐	☐	☐
12) Gostava de participar mais em actividades de organizações (ex. clubes desportivos, escuteiros, etc.).	☐	☐	☐	☐	☐

24. Com quem falas quando tens dúvidas ou questões relacionadas com a tua saúde/bem-estar?

a) Um(a) professor(a) ❒
b) Pai ❒
c) Mãe ❒
d) Irmã/Irmão ❒
e) Amigos ❒
f) Procuro informação via *internet* ❒
g) Outra pessoa ❒
Quem? _____
h) Não sou capaz de falar desses assuntos com familiares e amigos ❒

24.1. Onde falas quando tens dúvidas ou questões relacionadas com a tua saúde/bem-estar?

_____.

25. Quando tens dúvidas/questões relacionadas com a tua saúde/bem-estar, se tivesse que falar com um profissional com quem preferias falar?

a) Um(a) professor(a) ☐
b) Um(a) médico(a) ☐
c) Um(a) psicólogo(a) ☐
d) Um(a) assistente social ☐
e) Um(a) enfermeiro (a) ☐
f) Outra pessoa ☐
Quem? _____
g) Não sou capaz de falar desses assuntos com nenhum profissional ☐

25.1. Gostavas de ter contato com essa pessoa:

a) Na escola ☐
b) No centro de saúde ☐
c) Na junta de freguesia ☐
d) No hospital ☐
e) No centro da juventude ☐
f) Via telefónica ☐
g) Via *Internet* ☐
h) Noutro lado ☐
Onde?_____

26. Classifica a tua satisfação com os serviços prestados pelo hospital e/ou local de apoio clínico que costumas frequentar, assinalando uma resposta para cada linha.

	 Muito Fraca	 Fraca	 Razoável	 Boa	 Muito boa
1) Atendimento					
a) Tempo de espera da consulta	☐	☐	☐	☐	☐
2) Serviços médicos prestados					
a) Interesse do médico pelo meu problema de saúde	☐	☐	☐	☐	☐
b) Explicação da doença e tratamentos necessários	☐	☐	☐	☐	☐
c) Facilidade em contatar com o médico	☐	☐	☐	☐	☐
d) Acompanhamento e apoio do médico	☐	☐	☐	☐	☐
e) Tentar que seja o mais autónomo(a) possível	☐	☐	☐	☐	☐
3) Serviços de enfermagem prestados.					
a) Interesse do enfermeiro(a) pelo meu problema de saúde	☐	☐	☐	☐	☐
b) Explicação dos tratamentos	☐	☐	☐	☐	☐
c) Facilidade em contatar com o enfermeiro(a)	☐	☐	☐	☐	☐
d) Acompanhamento e apoio do enfermeiro(a)	☐	☐	☐	☐	☐
e) Carinho na realização dos tratamentos	☐	☐	☐	☐	☐
f) Tentar que seja o mais autónomo(a) possível	☐	☐	☐	☐	☐

27. Salienta dois aspetos mais positivos e negativos quanto aos serviços de saúde que recebeste.

Positivos:

1) _____;

2) _____.

Negativos:

1) _____;

2) _____.

28. Apresenta duas sugestões que possam melhorar o serviço de saúde.

1) _____;

2) _____.

29. Imaginando que no futuro deixarás de ser atendido na pediatria para ires a um atendimento de adultos, o que achas que poderia fazer com que esta transição fosse a melhor possível?

1) _____

_____;

2) _____

_____.

Finalizaste o teu questionário. Muito obrigada pela colaboração!

Equipa Aventura Social

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Chapter XVI

Supplemental Publications related to the Theme of this Thesis

Supplemental Publication A – Abstract

HEALTH-RELATED QUALITY OF LIFE IN ADOLESCENTS WITH CHRONIC CONDITIONS: HIGHLIGHTS FROM THE PORTUGUESE HBSC-2014

Teresa Santos • Margarida Gaspar de Matos • Tânia Gaspar • Maria Celeste Simões • Isabel Leal • Maria do Céu Machado

2015, *EIP – Excellence in Pediatrics, 7th Edition, Conference Programme, ID:182 / OP1-RD-CC:Presentation 2*, 66.
http://www.ineip.org/content/abstract/1524/op-182-2015-health-related-quality

Introduction: Living with a chronic condition during adolescence, where several changes occur (biological, psychological and social), is a major challenge for adolescents, that can, therefore, be at higher risk for vulnerable health outcomes.

Purpose: The main aim is to assess the impact of living with a chronic condition on health-related quality of life (HRQoL), psychological symptoms ("depression" - feeling low; "anxiety" - feeling nervous) and life satisfaction, comparing with healthy peers.

Materials and Methods: Using the HBSC 2014 database (cross-sectional survey), a representative sample of 6026 Portuguese adolescents (52.3% girls; average age: 14±1.7 years old), attending the 6th, 8th and 10th grades, and, randomly selected from 36 clusters of main stream schools (473 classes) were included. From these, 1022 adolescents reported to have a chronic condition (17.8%). The above study variables were respectively measured with KIDSCREEN-10, HBSC Symptom Checklist and Cantril's Ladder of Life Scale. Chronic condition was defined as a long-term disability, illness or medical condition that has been diagnosed by a doctor. Descriptive statistics and ANOVA was performed for the total sample, and a linear regression (controlling for age, gender, and FAS-Family Affluence Scale, an alternative measure for Socio Economic Status) was conducted only for the group of adolescents with chronic condition. The significance level was set at $p<0.05$.

Results: Adolescents with a chronic condition were more likely to have a poor HRQoL (75.63±14.0 *vs*. 78.23±13.3; $F(1,5754)=31.60$, $p<.001$)), higher frequency of reported symptoms of feeling low (4.40±1.1 *vs*., 4.16±1.3; $F(1,5755)=37.66$, $p<.001$)) and feeling nervous (3.96±1.3 *vs*. 3.56±1.4; $F(1, 5755)=75.58$, $p<.001$)), and worse life satisfaction (7.26±2.1 *vs*. 7.47±1.9; $F(1,5755)=8.90$, $p=.003$)), when compared with their healthy peers. The final adjusted regression model was statistically significant [$F(6, 934)=133.53$, $p<0.001$] and accounted for approximately 46% of the explained variance ($R^2=0.46$). A higher health-related quality of life was significantly associated with all the study variables: psychological symptoms, namely feeling low ($\beta=3.61$, $p<0.001$), and feeling nervous ($\beta=1.32$, $p<0.001$), and also with life satisfaction ($\beta=2.21$, $p<0.001$), being feeling low the most important one.

Conclusions: These findings highlight that the adolescents living with a chronic condition can be more vulnerable and may present a higher risk for poor HRQoL, psychological symptoms and life satisfaction, thus, more likely to need support and opportunities for a healthy youth development. Interventions should implement a "health assets" approach and take into account a more multifactorial understanding of the impact of a chronic health condition in adolescents, including the assessment of these variables and the promotion of a healthy psychological well-being.

Keywords: adolescent health, chronic condition, health-related quality of life, life satisfaction, psychological symptoms.

Supplemental Publication B –Articles

EXPERIMENTATION DU CANNABIS CHEZ DES ELEVES D'ULIS AVEC DEFICIENCE COGNITIVE

Dibia Liz Alfaro Pacoricona • Teresa Santos • Margarida Gaspar de Matos • Virginie Ehlinger • Stanislas Spilka • Mariane Sentenac • Emmanuelle Godeau, Emmanuelle

2016, *Courrier des Addictions (submitted)*

ABSTRACT

Globally, current inclusive education policies allow students with cognitive disorders to participate in community/school life, however, such an increasing exposition might raise their level of detrimental behaviours as well, namely substance use. This study aims to: 1) describe cannabis experimentation rates among cognitively impaired adolescents schooled in special units (ULIS) in junior high-schools, compared to mainstream students; and 2) to explore factors associated with substance experimentation among ULIS students.

A cross-sectional experimental study adapted from the international HBSC/WHO questionnaire was conducted among 700 ULIS students with a mean age of 14.2 years and 7023 students in mainstream junior high-school (mean age: 13.6). Only students aged 14 or more were considered in the analyses (382 ULIS students; 2642 mainstream junior high-school students).

The proportion of students in inclusive education enrolled in ULIS who have already experimented cannabis is not as high as among their non-disabled peers (9.1% among ULIS students *vs*. 20.9% among mainstream junior high-school students), yet is far from being negligible. Thus, to have epidemiological data on cannabis experimentation in intellectually disabled students is crucial to adapt interventions and policies to the cognitive level and specificities of this group of adolescents, in order to increase their chances and opportunities later in adulthood.

Keywords: adolescents; inclusive education; cannabis experimentation; cognitive impairment.

ADOLESCENTES COM DOENÇA CRÓNICA EM *SETTING* HOSPITALAR: PERSPECTIVAS QUALITATIVAS
[ADOLESCENTS WITH CHRONIC DISEASES IN A HOSPITAL SEETING: QUALITATIVE PERSPECTIVES].

Teresa Santos • Margarida Gaspar de Matos • Maria Celeste Simões • Maria do Céu Machado

2014, *Actas do 2º Congresso da Ordem dos Psicólogos Portugueses e IX Congresso Ibero-Americano de Psicologia*. Portugal: Lisboa *(accepted)*.

Resumo

A adolescência compreende um período evolutivo (dos 10 aos 20 anos), de profundas mudanças biopsicossociais, que podem ser mais acentuadas na presença de uma doença crónica (DC) e suas limitações. As respostas de adaptação são variáveis e dependem de diversos factores individuais e específicos de cada jovem e do seu contexto de vida.

A investigação comparando adolescentes com ou sem DC, ou comparando jovens com diferentes doenças, tem sido contraditória, não confirmando uma relação direta entre o sofrimento e a doença/perturbação.

Este trabalho procura apresentar qualitativamente os principais resultados de adolescentes e pais, relacionados com a satisfação com os serviços prestados pelo hospital, bem como os aspectos positivos e negativos do mesmo. São também abordadas as principais sugestões para que a transição para o serviço de adultos seja feita da melhor forma possível, bem como sugestões de melhoria dos serviços de saúde, da escola e na comunidade, no que diz respeito ao apoio a situações de condição crónica na adolescência.

Os resultados principais visam obter informação pertinente sobre estas áreas, procurando "dar voz aos adolescentes e pais" de forma a contribuir para elaboração de programas de intervenção mais eficazes e adequados às suas necessidades dos jovens e pais, ao longo do processo de adaptação a uma condição de saúde crónica.

Palavras-chave: doença crónica; promoção da saúde; qualidade de vida; satisfação com serviços; abordagem qualitativa.

Abstract

Adolescence comprises an evolutionary period (from 10 to 20 years), where typical deep bio and psychosocial changes occur. Those changes can be even more pronounced in the presence of a chronic disease (CD) and its limitations. Adaptive responses are variable and depend on many specific factors related to each adolescent and his own individual's life context.

Research comparing adolescents with or without DC, or comparing adolescents with various diseases, have been contradictory, not confirming a direct relationship between suffering and disease/disorder.

This work aims to present the main qualitative results related to the evaluation of the satisfaction of adolescents and parents, concerning the services provided by the hospital, as well as positive and negative aspects of it. It also identifies major suggestions to make the transition to adult's services the best possible, and ideas to improve health, school and community services, regarding the support to chronic conditions in adolescence.

Principal results try to find relevant information about these areas, intending "to give voice to teens and parents", in order to contribute to the development of more effective intervention programs. Therefore, more suitable for the needs of adolescents and parents, throughout the process of coping with a chronic health condition.

Keywords: chronic disease; health promotion; quality of life; satisfaction with services; qualitative approach.

Introdução

O período da adolescência (10 aos 20 anos) é caracterizado por profundas mudanças biopsicossociais, que podem ser mais acentuadas quando se vivencia uma situação de doença crónica (DC), bem como as limitações inerentes. As respostas de adaptação dos jovens a estas situações clínicas são variáveis e dependem de diversos factores individuais e específicos de cada um, bem como dos seus contextos de vida (Barros, 2008).

De forma geral, consideram-se doenças crónicas todas as doenças prolongadas e irreversíveis, com um decurso prolongado que pode ser fatal ou estar associado a duração de vida relativamente normal, embora com um funcionamento físico ou psicológico debilitado (Barros, 2009). Uma doença considera-se crónica quando interfere com o funcionamento normal diário por um período maior do que três meses num ano ou resulta em hospitalização por mais de um mês num ano, ou, quando ocorrem simultaneamente ambas as condições (Newachech & Taylor, 1992). Não é consensual a definição de quais as doenças consideradas como crónicas, porém, as que surgem com maior prevalência na adolescência são as situações de asma, doença cardíaca congénita, epilepsia e diabetes (Barros, 2009).

Apesar dos avanços na medicina, os jovens com doença crónica parecem ser ainda um grupo vulnerável e estar em maior risco de um desenvolvimento psicológico não saudável (Verhoof, Maurice-Stam, Heymans & Grootenhuis, 2012) e de maiores dificuldades de ajustamento (Oeseburg, Jansen, Groothoff, Dijkstra, & Reijneveld, 2010), sendo que a sua participação nos principais contextos de vida pode ser condicionada (WHO, 2001; Simões, Matos, Ferreira, & Tomé, 2010).

Na área da saúde, a comunidade científica tem vindo a estabelecer um debate sobre a legitimidade da investigação qualitativa, sendo cada vez mais demonstrada a sua importância e utilidade. De facto, a abordagem qualitativa permite apreender alguns aspectos sobre o "mundo" social e gerar novos conhecimentos aplicáveis ao mesmo. Os actores são considerados como indispensáveis para a compreensão dos comportamentos sociais e existe uma tentativa de aprofundar as contradições e dilemas que atravessa a sociedade concreta, analisando experiências e o sentido das acções, através de entrevistas semi-estruturadas, observações participantes, diários e grupos focais. Desta forma, as abordagens qualitativas podem trazer mais-valias à investigação, nomeadamente uma visão naturalista, validade ecológica e centrada na experiência individual dos participantes (Willig, 2013).

Na área da doença crónica é importante a existência de intervenções que ajudem a explorar o significado e aceitação da doença. Estas abordagens identificaram alguns temas pertinentes para os jovens, tais como a importância de desenvolver e manter amizades, ser "normal" e prosseguir com a vida, a importância da família e de experiências escolares, a atitude perante o tratamento, relacionamento com os profissionais de saúde, e o futuro (Taylor, Gibson, & Franck, 2008; Taylor, Franck, Dhawan, & Gibson, 2010). Outro tema igualmente pertinente relaciona-se com o momento de passagem para vida adulta, que pode implicar a gestão de aspectos tais como "viver uma vida mais curta", o binómio da dependência *vs* independência e a constante "luta" entre o "ser normal" vs "ser diferente" (Cura, 2012). No que diz respeito a esta questão, as metodologias qualitativas permitiram ouvir as necessidades dos jovens, nomeadamente a realização de discussões prévias sobre a questão da transição, a promoção de oportunidades de visitas-guiadas ao novo espaço e o relacionamento com a equipa de técnicos de saúde (Tuchman, Slap, & Britto, 2008).

A investigação qualitativa nesta área salienta ainda que é fundamental "dar voz" às crianças e jovens com doença crónica, pois eles são descritos como intérpretes competentes do seu "mundo" (Sartain, Clarke, & Heyman, 2000; Serrabulho, Matos, & Raposo, 2012).

Para além dos próprios jovens, os pais assumem também um papel relevante na promoção da adaptação à doença crónica (Simões, Matos, Ferreira, & Tomé, 2009), sendo que ainda com variações consoante

o grau de severidade da doença, intensidade dos tratamentos e limitações da rotina, é toda uma realidade que se modifica, implicando a necessidade de recursos que permitam a aceitação destas transformações (Santos, 2012).
O presente trabalho pretendeu precisamente dar oportunidade aos jovens e pais para expressarem as suas ideias, opiniões e necessidades relativamente à satisfação com os serviços.

Metodologia

Participantes

Os participantes são 135 adolescentes Portugueses (52.6% rapazes) com doença crónica (diabetes: N=31.9%; asma/alergias: N=45.9%; patologia neurológica: N=22.2%), média de idade de 14 anos (*DP*=1.5; *Mín*=12; *Máx*=16) e que são acompanhados na Consulta Externa de Pediatria do Centro Hospitalar de Lisboa Norte (CHLN) - Hospital de Sta. Maria (Especialidades de Alergologia, Diabetes e Neurologia). Estes adolescentes são maioritariamente da zona de Lisboa e Vale do Tejo (84.4%) e têm nacionalidade Portuguesa (97.8%).

Instrumentos

Foram usadas questões abertas para adolescentes e pais, que versavam a sua avaliação da satisfação com os serviços. As questões estão descritas na Tabela 1.

Tabela 1: Questões abertas sobre Avaliação dos Serviços (adolescentes e pais).

Questões	Aplicação
Salienta/e dois aspectos mais positivos quanto aos serviços de saúde que recebeste/recebeu.	Jovens e Pais
Salienta/e dois aspectos mais negativos quanto aos serviços de saúde que recebeste/recebeu.	Jovens e Pais
Apresenta/e duas sugestões que possam melhorar o serviço de saúde no hospital.	Jovens e Pais
Imagina/e que no futuro irá ser feita a passagem da pediatria para o serviço de adultos, o que achas/a que poderia fazer com que esta transição fosse a melhor possível?	Jovens e Pais
Apresente duas sugestões que possam melhorar o serviço de saúde na escola.	Pais

Procedimento

Em conjunto com os médicos especialistas da consulta de Alergologia, Diabetes e Neurologia, os jovens e pais foram selecionados para participarem no estudo, respondendo às questões antes ou depois da consulta externa. Foram seleccionados os jovens/pais de acordo com os seguintes critérios: estar entre os 12 e os 16 anos de idade, ter uma doença crónica e capacidade de autonomia da resposta. A participação era voluntária e foi elaborado um Acordo e Consentimento Informado para os Encarregados de Educação e também para os jovens maiores de 14 anos.
Relativamente às questões abertas, foi realizado um pré-teste (em escolas) com um grupo de alunos das mesmas faixas etárias, mas sem doença crónica, e, posteriormente uma avaliação por um grupo de especialistas dentro da área. O projecto foi submetido e aceite pela Comissão de Ética para a Saúde do CHLN

Análise de Dados

As respostas às questões abertas foram submetidas a uma análise qualitativa realizada através do *software* NVIVO. Procedeu-se à categorização de respostas e criação de uma árvore de categorias/nós,

seguindo-se a consulta da frequência de palavras. Foram utilizados o resumo e a nuvem de palavras para a exploração do conteúdo das respostas.

Resultados

No que diz respeito à questão *Salienta/e dois aspectos mais positivos quanto aos serviços de saúde que recebeste/recebeu*, as respostas dos jovens e dos pais têm uma grande semelhança centrando-se na facilidade em contactar os médicos/enfermeiros e esclarecer dúvidas; no interesse, disponibilidade, explicação e atendimento médico/enfermagem; no profissionalismo, simpatia e atenção. É ainda salientada a importância do carinho dos enfermeiros na realização dos tratamentos.

Na questão *Salienta/e dois aspectos mais negativos quanto aos serviços de saúde que recebeste/recebeu*, as respostas de pais e jovens convergem igualmente em termos de conteúdo e focam sobretudo o tempo de espera da consulta/tratamentos, as condições das instalações (exp: excesso de pessoas, desconforto, barulho, comunicação, estacionamento), bem como lacunas ao nível dos recursos humanos e logísticos.

Também na pergunta *Apresenta/e duas sugestões que possam melhorar o serviço de saúde no hospital*, pais e jovens apontam sobretudo para a necessidade de maior articulação da informação entre médico/enfermeiro; existência de apoio psicológico na fase inicial do diagnóstico e fases seguintes; diminuição do tempo de espera e melhoria das instalações/actividades durante esse tempo; disponibilização de mais médicos e enfermeiros, meios financeiros e humanos.

Relativamente à questão *Imagina/e que no futuro irá ser feita a passagem da pediatria para o serviço de adultos, o que achas/a que poderia fazer com que esta transição fosse a melhor possível?*, pais e jovens indicam que seria importante manter o mesmo médico e equipa de saúde, sugerindo uma passagem progressiva entre os serviços, bem como ligação entre as equipas de Medicina e Enfermagem. Foi também sugerida a manutenção do mesmo interesse, carinho e atendimento. Os pais salientam ainda a necessidade de continuarem presentes no processo e a receber informações clínicas, apesar dos filhos posteriormente se encontrarem no serviço de adultos.

Por fim, a questão *Apresente duas sugestões que possam melhorar o serviço de saúde na escola* (apenas feita aos pais) aponta para uma necessidade de mais informação/formação dos professores e da comunidade escolar sobre doenças crónicas, incluindo formação específica em 1os socorros ou situações de emergência (em DC) para os auxiliares de ação educativa. Sugere-se ainda a criação de serviços de saúde nas escolas, a colocação de mais psicólogos e o enfoque na escola como um espaço privilegiado para esclarecer e debater dúvidas.

Discussão

No presente trabalho procurou-se evidenciar a satisfação de jovens com doença crónica e seus pais relativamente à satisfação dos serviços de saúde e também sugestões para o contexto escolar, focando nos aspectos relacionados com a DC.

Verificou-se que quando questionados sobre as suas necessidades, os jovens são capazes de dar respostas objectivas e pertinentes, bem como sugestões válidas para a intervenção. Igualmente a opinião e sugestões dos pais são cruciais, evidenciando-se o seu papel no contexto de adaptação à doença e na adesão aos tratamentos.

Salienta-se assim a importância em "dar voz" e envolver as crianças e jovens com doença crónica, como uma forma mais eficaz de um processo continuado de melhoria de cuidados.

Desta forma, podem ser planeadas intervenções cada vez mais individualizadas e focadas nos objectivos e necessidades que os próprios jovens consideram pertinentes, potenciando as questões de custo/benefício das mesmas.

Agradecimentos

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Contato para Correspondência

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ESTILOS PARENTAIS E DESENVOLVIMENTO POSITIVO EM CRIANÇAS E ADOLESCENTES COM DOENÇA CRÓNICA
[PARENTING STYLES AND POSITIVE DEVELOPMENT IN CHILDREN AND ADOLESCENTS WITH CHRONIC CONDITION]

Teresa Santos • Margarida Gaspar de Matos • Maria Celeste Simões • Inês Camacho • Gina Tomé • Mª Carmen Moreno

2014, *Revista de Psicologia da Criança e do Adolescente, Journal of Child and Adolescent Psychology, 4*(2), 185-204. http://revistas.lis.ulusiada.pt/index.php/rpca/article/view/429/409

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RESUMO

A adolescência compreende um período de profundas mudanças biopsicossociais, que pode ser agravado na presença de uma doença crónica e suas limitações. Os modelos educativos/família influenciam fortemente os comportamentos e a socialização, tendo um papel decisivo no desenvolvimento da criança. Papel ainda mais relevante perante uma situação de doença crónica, oscilando entre: necessidades de proteção da saúde, e, de autonomização e responsabilização.

O presente artigo tem como objetivo uma abordagem teórica sobre vinculação e estilos parentais, relacionando a sua relevância na adaptação à doença crónica em adolescentes. Foram explanados os vários tipos de estilos parentais, bem como sucintamente enquadradas as principais características de uma condição crónica na adolescência, e, estilos parentais mais eficazes durante o processo de adaptação. Estilos parentais restritivos foram identificados como obstáculos a uma boa adaptação dos jovens com doença crónica, enquanto que um estilo parental democrático se apresenta como facilitador da adaptação à doença.

A família é um alvo de intervenção crucial numa situação de condição crónica, devido à relação de dependência numa idade em desenvolvimento e também ao impacto para a criança e ambiente familiar. Por sua vez, os pais devem também facilitar a comunicação com os filhos, ajudando-os a adquirir competências de autonomia e monitorização face à doença crónica. Por fim, salienta-se que, cada vez mais é importante "dar voz" aos jovens com doença crónica, de forma a ouvir as suas necessidades, conhecimentos, competências e direitos específicos, e, sobretudo, porque são intérpretes competentes do seu "mundo".

Palavras-Chave: adolescentes; doença crónica; estilos parentais; promoção da saúde

ABSTRACT

Adolescence consists of profound bio-psychosocial changes that can be made worse in the presence of a chronic illness and its limitations. Educational models /family strongly influence behaviors and socialization, having a decisive role in child development. Family's role becomes even more relevant in a situation of chronic condition, oscillating from health protection needs, to autonomy and empowerment.

The aim of this paper is to describe a theoretical approach of attachment and parenting styles, and its association and relevance in adaptation to chronic condition in adolescents. Various types of attachment and parenting styles were explained, as well as succinctly explored the main characteristics of a chronic condition in adolescence. In addition, the more effective parenting styles during the adaptation process were also described.

Restrictive parenting styles were identified as obstacles to a good adaptation of adolescents with chronic condition; on the other hand, an authoritative parenting style presents itself as a facilitator for adaptation. Family is a crucial target for interventions in a situation of chronic condition, due to age dependency level in the development process, and also because of the impact on the child and family environment. In turn, parents should also facilitate communication with children, helping them to acquire skills and autonomy to face chronic condition's management. Finally, it is noted that it is increasingly important to "give voice" to young people with chronic condition, in order to listen to their needs, knowledge, skills and specific rights, and especially because they are competent interpreters of their "world".

Key-words: adolescents; chronic condition; health promotion; parenting styles

Supplemental Publication C – Chapter of Books

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